

**Occupations of citizenship:
The missing layer in empowered engagement
between rural people with disabilities
and primary healthcare workers in South Africa**

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“Baqqithisa itole kunina”

They allow the calf to pass through the gate to its mother.

“‘Itole’ is the calf of a cow. At night you separate the calf and cow, so that you can milk the cow in the morning. Then in the morning, if you don’t want to milk the cow, you just let the calf go straight to the mother so he can suckle. *Ukugqithisa* means to allow him to pass, to allow the calf to go to its mother... So you are there to milk the cow, but instead you are just letting the calf through, not milking. You look like you are going to do your job, but you are not actually doing it.”

- Xaks Dabula (co-researcher)

Abstract

Background:

People with disabilities in impoverished rural areas of South Africa struggle to access healthcare, despite the right to health established by the Constitution and the United Nations Convention on the Rights of Persons with Disabilities. Health system challenges and structural conditions of poverty impact this group in specific ways, with implications for households and communities that are not well understood. To date, health systems research and design have largely omitted disability considerations.

Primary health care (PHC) calls for community engagement with health systems, to voice local needs, influence service provision, and hold providers to account. However, current models of community engagement rely on certain political, social and economic conditions, which are not present for rural people with disabilities in South Africa.

Purpose:

This study sought to understand the existing engagement between rural people with disabilities and healthcare workers in the PHC interface, and thus to theorise how this could be strengthened for more responsive and equitable services.

Methods:

A qualitative, ethnographic embedded case study was undertaken with eleven people with disabilities and their households in a rural village in the Eastern Cape Province. We followed their narratives of engaging with PHC services over time, applying an occupational lens, framed within the capabilities approach, to understand how these stories unfolded in the context of their lifeworld.

Findings:

The resource-intensive process of seeking healthcare often culminated in a formulaic encounter with healthcare workers (termed ‘futile reproduction’), which failed to engage with the complex needs of people with disabilities. Over time, this created a cycle of ‘capability suck’. Healthcare seekers, constrained from challenging unsatisfactory service, adopted a cautious approach of ‘quiet autonomy’. By contrast, where healthcare workers adopted a reciprocal, mutually respectful style of engagement, (‘collaborating to heal’), encounters could be startlingly effective and empowering, leading to ‘capability release’.

Conclusions

Relational dimensions of healthcare proved especially powerful for rural people with disabilities. PHC reforms in South Africa could strengthen engagement by bringing care into the rural life context, incorporating longitudinal relationships into service design, and including disability training and rehabilitation workers in PHC teams.

Key words

Capabilities

Disability

Empowered engagement

Health systems

Occupations

Primary health care

Plagiarism declaration

I, **Kate Sherry**, hereby declare that the work on which this thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university. I authorise the University to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signature:

Signed by candidate

Date: 15th February 2016

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“The eyes of the Lord are on the righteous, and his ears are attentive to their cry...

The Lord works righteousness and justice for all the oppressed” (Ps 34:15; Ps 103:6)

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Note: All currency amounts are expressed in both South African rands (R), and US dollar equivalent (US\$). Conversions used the exchange rate of US\$1 = R15,84, recorded on 14/02/2016 (XE.com 2016).

Abbreviations/acronyms

CBR: Community-Based Rehabilitation

COPASAH: Community of Practitioners on Accountability and Social Action in Health

DHS: District Health System

DPSA: Disabled People South Africa

EQUINET: Regional Network for Equity in Health in East and Southern Africa

GDP: Gross Domestic Product

HAART: Highly Active Antiretroviral Therapy

HIV/AIDS: Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome

HPSR: Health Policy and Systems Research

ICF: International Classification of Functioning, Disability and Health

LMIC's: Lower and Middle Income Countries

MNS disorders: Mental Health, Neurological and Substance abuse disorders

NGO: Non-governmental Organisation

PDO: Poverty, Disability and Occupation

PHC: Primary Health Care

PMTCT: Prevention of Mother to Child Transmission (of HIV)

PPP: People informing Policy: Power and Progress

SANPAD: South Africa Netherlands Partnership for Alternatives in Development

SASSA: South African Social Security Agency

TARSC: Teaching and Research Support Centre

TB: Tuberculosis

UCT: University of Cape Town

UNCRPD: United Nations Convention on the Rights of Persons with Disabilities

WHO: World Health Organisation

Definition of terms

Agency: the making of choices “to pursue goals that one values and has reason to value” (Deneulin & Shahani 2009, p31). In the study, this included people’s choices to seek healthcare (or not), the ways this was achieved, and the valued goals underlying these efforts.

Community engagement: the variety of activities in which citizens engage with health services to voice their needs and opinions, influence planning and control of services, and hold government to account for their right to the highest attainable standard of health. ‘Engagement’ is used in preference to ‘participation’, as the latter may imply ‘joining in’ with health system agendas rather than communities setting their own (Nickson 1991).

Context: dynamic interplay of social, physical, temporal, historical, cultural, institutional and spiritual factors that make up participants’ life-space, including “the relationships between [these factors] that influence the meaning of a task, activity or occupation for the performer” (Creek 2010, p 25).

Disability: Experience of participation restriction and activity limitation arising from the dynamic interactions between a person with a health condition and the context in which they live, including the health system (World Health Organisation 2001; World Health Organisation 2011). People with disabilities in the study included those with sensory, physical, neurological and mental health impairments.

Empowerment: the process of expanding people’s opportunities to exercise agency and realise their choices. Empowerment is understood to include personal factors such as motivation, skills and knowledge, as well as opportunity structure. It is situation-specific and relational (Samman & Santos 2009).

Empowered engagement: all interactions between people with disabilities and health services in which they experience freedom to pursue and realise their own valued goals through the engagement (self-defined).

Health: the capability set which represents to a person or community the combination of beings and doings they most value and have reason to value, given their available resources and opportunities (Law & Widdows 2008). Health is complex, multi-dimensional and personally defined. It includes both ‘elementary’ functionings, such as the ability to be free from disease and pain, and complex functionings, such as the ability to fulfil valued social roles (Ariana & Naveed 2009).

Health systems: “all organizations, people and actions whose primary intent is to promote, restore or maintain health” (World Health Organization, 2007, p2). In this study, ‘health system’ is used to refer primarily to the activities of the South African Department of Health, including national, provincial and local spheres of government.

Occupation: “chunks of culturally and personally meaningful activity that can be named in the lexicon of the culture” (Clark et al. 1991, p30).

Participatory space: Physical, social, temporal and functional space that offers a moment of opportunity for people to engage with health services in pursuit of their valued goals (self defined).

Poverty: Multi-dimensional capability deprivation, including material deprivation and lack of choice and opportunities, as well as experiences of powerlessness and social marginalisation (Deneulin &

Shahani 2009). Chronic poverty is enduring, cumulative in its effects, and inter-generationally transmitted (Hulme & Shepherd 2003).

Primary health care: Essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation” (World Health Organisation 1978, p1-2). In the study, PHC services were taken to include community-level, clinic and district hospital services (LeRoux & Couper 2015).

Rehabilitation: “A set of measures which enables people with disabilities to achieve and maintain optimal functioning in their environments” (World Health Organization 2010a, p8). In the study context, this referred mainly to services within the health sector provided by occupational therapists, physiotherapists, speech and language therapists and audiologists, although availability was very limited. Rehabilitation in this sense is one component of community-based rehabilitation, which is a broad, multisectoral strategy for inclusive development (World Health Organisation 2010b)

Rural: Areas which are spatially, socially and economically peripheral, in relation to the opportunities and resources of society (self-defined). In this context, rural areas were also characterised by lack of infrastructure, presence of traditional authorities, communal land ownership and poor access to healthcare.

Situation: “the multi-faceted, spatially and temporally dependent events that provide the basis of active experience” (Cutchin 2004, p 305). A person’s situation includes the specifics of a time, place and problem arising within the unfolding narrative of his life. In our study, the situations of interest were the marked by the emergence of a health need for a person with a disability, which gave rise to healthcare seeking (or a choice not to do so).

Chapter 1: Introduction

1.1. Introduction

People with disabilities in South Africa have their right to health enshrined in the Constitution (South Africa 1996), and in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations 2006). Health is a prerequisite for other socio-economic, civil and political rights, and yet for many South Africans, this right is not realised within the current context of persistent poverty and available health services. People give expression to their needs and aspirations and engage with their lived environments through the ordinary things that they do every day, i.e. their occupations. The practice of citizenship, including accessing rights and enacting responsibilities, likewise occurs through human engagement in occupation, in the context of state policy and services, as well as the physical, social economic and political environments within which people live. Occupations of citizenship, including access to healthcare, may be enabled or obstructed by conditions of poverty, inequality and disability, as well as by health system design. To be equitable, health systems must be responsive to the local needs of vulnerable groups, and take account of contextual influences on how people meet their daily needs and engage with health services.

People with disabilities enact their right to health at a micro level, within the participatory spaces created where communities interface with the health system. Primary health care (PHC) provides the framework for these spaces, prioritising empowered engagement by healthcare seekers, health service responsiveness to local needs and realities, and appropriate, efficient and comprehensive care (World Health Organisation 1978). At present, health services in rural areas of South Africa are failing to fulfil PHC principles, with particular impact on people with disabilities and their households. Little is known about the nature and extent of this impact, or how the system could be strengthened to overcome it.

This research offers a detailed study of people with disabilities and their households in a remote rural village in the Eastern Cape province of South Africa, exploring their engagement with the PHC system over time. By adopting an occupational perspective, framed within the capabilities approach, it is possible to uncover how healthcare seeking is embedded in daily life, shaped by the ‘degree of fit’ between person, context and health system.

1.2. Positioning the researcher

This study came about as a culmination of my work as an occupational therapist in the former Transkei “homeland¹” region of the Eastern Cape. In 2006 I became employed at a state-run district hospital in a remote rural community. As their first permanent rehabilitation professional, I was tasked with setting up services that would come to include occupational therapy, physiotherapy, speech therapy, audiology and access to assistive devices, serving a catchment population of 130 000 people.

I grew up as a white English-speaking woman in urban Cape Town, and qualified as an occupational therapist just seven years after the country’s transition from Apartheid rule to democracy. Throughout my time at the hospital (three and a half years, followed by a year and a half in a community-based project in the same area), I found the rural context alien and extremely difficult to understand. The former Transkei has a complex socio-political history, and remains the heartland of Xhosa culture,

¹ Homelands, or bantustans, were designated by the Apartheid government as areas for the ‘separate development’ of indigenous black nations.

which is entrenched in the tribal leadership and communal land ownership system still in force in this area. Very few of my patients² spoke English, and the isiXhosa I learnt in the city and from books bore little resemblance to the 'deep' version of the language spoken here. At the same time, I encountered the challenges of the state health system, notoriously inefficient and poorly managed in this district, and at a local and national level, unsupportive of rehabilitation services. I was part of a tiny team of health professionals, few of whom had previous exposure to occupational therapy or rehabilitation, and our work was governed by the powerful and entrenched biomedical paradigm. My colleagues, focused on saving lives threatened by HIV, TB and childhood malnutrition, had little interest in what I as an occupational therapist saw as critical: the possibility for people with physical, psychosocial and sensory impairments to live their lives with dignity as full citizens and included members of their communities³.

Since that time, I have undertaken various roles as a clinical consultant, researcher and health activist in the rural Eastern Cape. Each experience has deepened my conviction of the significance of disability for health system design, and more broadly for rural development and poverty alleviation. The rights of poor communities in rural areas are systematically violated, both through living conditions that perpetuate poverty, and through the administrative injustices of a foundering bureaucracy. People with disabilities are excluded from the few opportunities that do exist, and seem invisible to the healthcare workers and officials working in the area. At the same time, I have been painfully aware of my own lack of insight into the situation, and this sense of inadequacy and resulting feeling of 'missing the mark' as a healthcare provider, led to the research question for this study.

1.3. Background to the study

South Africa's nascent democracy, Constitution and civil liberties are widely celebrated, even as their failure to bring freedom to the majority thus far is acknowledged. The injustices of oppressive Apartheid era legislation have given way to administrative injustices, in the current government's failure to translate progressive policies into practice. The gulf between rights and realities for the majority is deeply alarming, and the gap between the poor and the wealthy continues to widen (Marais 2011).

The idea of bottom-up change, through the voice and action of the people themselves, pervades policy rhetoric across the many fields of public service, including health. The South African Constitution provides for equality of all citizens before the law, the protection of human rights, and a single shared citizenship in a unified nation. The decentralisation of government to provincial and local level aims to deepen democracy and local autonomy, and mechanisms for citizen participation are built into state institutions as diverse as schools, police and health institutions. At the same time, civil unrest and dissatisfaction with the government is widespread and seemingly growing. 'Service delivery protests', sometimes in violent and destructive forms, prevail across the country, where communities still await access to clean water, sanitation, electricity and housing (Gibson 2011). The relationship between people and state is conflicted and ambiguous. The government has not 'delivered', but complaints also arise that people are not doing things for themselves, not taking responsibility for their lives. This sense of ambiguity in relationship between government and citizen, framed uncomfortably as 'provider' and 'user', also pervades the public health system. State failures to

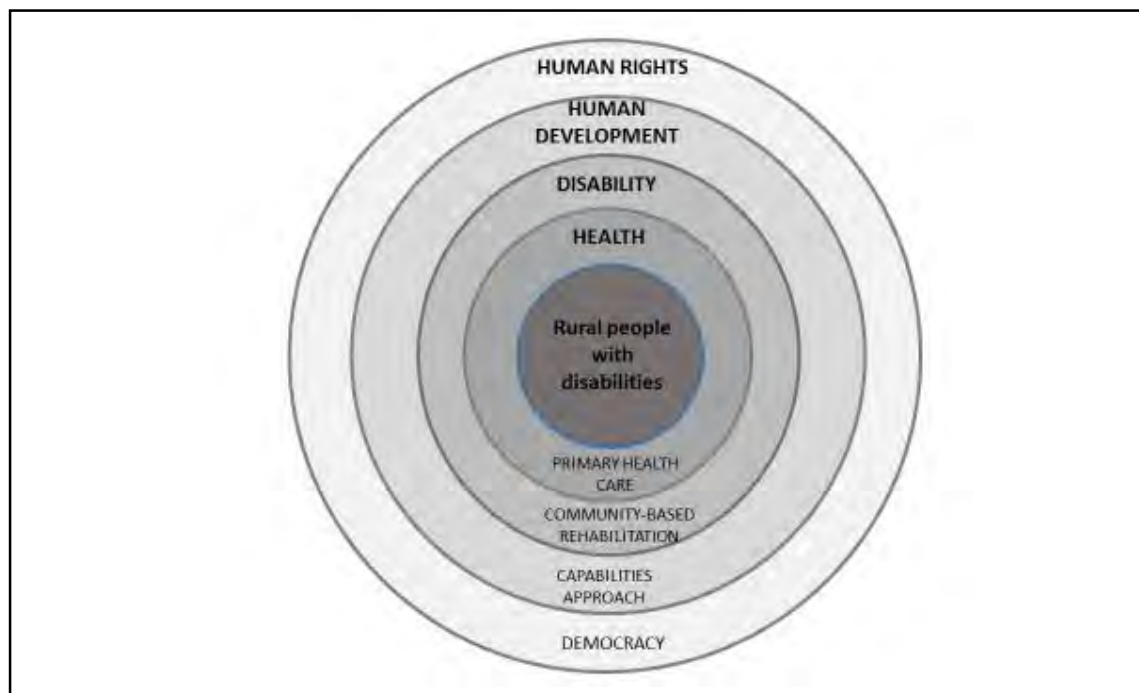
² Although the term 'patient' is controversial, I use it here to denote the typical relationship between healthcare workers and healthcare seekers in this context.

³ I'm happy to say that ten years on, my medical colleagues at the hospital are enthusiastic advocates for rehabilitation.

‘deliver’ adequate healthcare for the majority stand in tension with emphasis on people’s personal responsibility for their health, through their life choices and daily activities, particularly in the context of the HIV/AIDS epidemic and the growing burden of non-communicable diseases (NCD’s). At a broader level, the living conditions of many South Africans far outweigh personal choice in determining their (ill) health. While this situation has its roots in the legacies of the Apartheid era and earlier colonial administrations (Coovadia et al. 2009; Ataguba & Alaba 2012), progress in the twenty years since the transition to democracy has been limited and highly uneven.

The study is framed within a number of overlapping constructs, which are represented in Figure 1 as a series of concentric circles, each nested within the larger, creating the specific focus of the research. The outermost circle represents the overarching paradigm of human rights, which finds its socio-political expression in the democratic system, based on principles of equality and equal opportunities. Both were established in South Africa with the fall of Apartheid in 1994, and yet neither has been fully realised for all South Africans. Human rights become realised through the process of human development, understood here in Sen’s terms (i.e. the capability approach) (Sen 1999; Deneulin & Shahani 2009). Disability, the core focus of the study, is defined primarily as an issue of human rights and development, as articulated in the philosophy of community-based rehabilitation (CBR) (World Health Organisation 2010). Primary health care (PHC) shares with CBR the principles of human rights, equity and participatory development, and shapes the view of health systems adopted in the study (World Health Organisation 2008b). At the centre of the circle is our study population, namely rural people with disabilities.

Figure 1: Framing the study



The following sections will elaborate on these elements to introduce the rationale for the study.

1.3.1. Human rights

The South African Constitution of 1996 enshrined the basic political, civil and socio-economic rights of all citizens, without discrimination on the basis of race, age, gender or disability, among other factors (South Africa 1996). The rights and responsibilities of citizens within this democracy include active engagement with government to influence policy and hold state actors to account, both at national and local level. The devolution of power to local government, including district health authorities, has been an important structural move to support this process.

During the first years of democratic rule, the politically active national disability movement successfully lobbied for a range of highly progressive policies, including legislation on access to education, healthcare, employment and social welfare (Watermeyer et al. 2006). In 2007, South Africa was one of the first countries to ratify the Convention on the Rights of Persons with Disabilities (United Nations 2006), expressing a commitment to disability rights not only to its citizens but also to the international community. Unfortunately, these progressive actions in the policy realm have not translated into reality for the majority of people with disabilities in South Africa. Although a large proportion of the population still lack access to the basic conditions of a healthy and dignified life, people with disabilities are systematically disadvantaged even within other marginalised communities. Dimensions of age, race, gender and geospatial location intersect with the disability experience to create multiple and complex experiences of deprivation and ultimately, human rights violations (Emmett 2006; Duncan et al. 2011b; Duncan & Watson 2009).

1.3.2. Human development and poverty

Poverty is a multi-dimensional construct, including not only material and income deprivation, but also experiences of social exclusion, discrimination, voicelessness and lack of control over one's life (Narayan, Chambers, et al. 2000). While some experience episodes of transient poverty from which they recover, the poverty of concern here is chronic, intergenerationally transmitted, and entrenched (Hulme & Shepherd 2003). It is estimated that 45,5% of South Africans live in poverty⁴ and 20,2% in extreme poverty⁵, with the majority of these being female, black and rural (Statistics South Africa 2014b). While international evidence indicates overrepresentation of people with disabilities among the chronically poor, little is known about this relationship in South Africa (Mitra et al. 2013; Eide & Ingstad 2013).

Amartya Sen's capabilities approach has been influential in shifting the understanding of poverty from an income-related construct to one of multi-dimensional deprivation. It describes development as freedom for people to do and be things they value and have reason to value (Sen 1999). This approach informs the study, providing a framework within which human agency is central. Agency is defined in Sen's terms as the ability to make and pursue choices about the things one values and has reason to value (Deneulin & Shahani 2009). Empowerment, as a complementary construct, is seen as the real increase in people's opportunities to exercise and realise these choices (Samman & Santos 2009). Little is known about the ways in which empowerment is enacted by rural people with disabilities at the micro level.

⁴ Poverty is defined here in terms of the upper-bound poverty line set at R620 (US\$39) per capita per month in 2011 (Statistics South Africa 2014b)

⁵ Extreme poverty is defined by income below the Food Poverty Line, set at R321 (US\$20,20) per capita per month in 2011 (Statistics South Africa 2014b)

1.3.3. Disability

The relationship between disability and poverty is described as complex, bi-directional and residing in multiple mechanisms and factors (Mitra et al. 2013; Elwan 1999). It is highly context-dependent, and there is little evidence on the relationship among poor rural communities in South Africa. Disability is defined here as the experience arising from the interaction between a person with an impairment (physical, psychosocial, sensory or a combination of these) and their environment (World Health Organisation 2001). The 'degree of fit' between person and environment gives rise to activity limitation (i.e. functional impairment), which may result in participation restriction, or exclusion from valued roles in society (World Health Organisation 2001). This understanding shifts disability from previously held biomedical and welfare paradigms, into the realm of human rights and development (World Health Organisation 2011). Community-based rehabilitation (CBR) is a multi-sectoral strategy for social inclusion, poverty alleviation and inclusive development, championed by the World Health Organisation and others as the gold standard for action on disability. CBR encompasses action across five domains or sectors, namely education, health, livelihoods, social life and empowerment. It is envisaged as a complex, locally specific set of processes, carried out by a range of agencies and actors, with the full participation of people with disabilities⁶ and their families⁷ (World Health Organisation 2010). Although the South African government's commitment to CBR has been inconsistent at best (Department of Health 2015), this study takes CBR as a reference point for interpreting disability and health systems within community development.

Estimates of the prevalence of disability in South Africa vary between 7,5% (Statistics South Africa 2014a) and 25% (World Health Organisation 2011), but these are based mainly on measurements of impairment and activity limitation, and may fail to capture the extent to which deprived rural environments exacerbate disability in these settings. Despite progressive action on disability rights at national level, the construct has been poorly integrated into relevant policy across sectors, including health (MacLachlan et al. 2012; Hanass-Hancock et al. 2013; VanRooy, E. Amadhila, et al. 2012).

1.3.4. Primary Health Care

PHC was first propounded as a revolutionary philosophy of healthcare based on close engagement with communities, responding to local needs and priorities, comprehensive and integrated healthcare and intersectoral action on the social determinants of health (World Health Organisation 1978). After several decades in which its broad vision was replaced by reductive, technical approaches to specific health conditions, PHC is returning to both international and local prominence in response to the complex array of new challenges facing health systems (World Health Organisation 2008b; Bhatia & Rifkin 2013).

South Africa's health system has historically been weighted towards urban, hospicentric care, with marked inequities in resourcing, coverage and quality between regions and population groups (Coovadia et al. 2009; McIntyre & Gilson 2002). These challenges continue to plague the system today, compounded by a so-called quadruple burden of disease which includes the HIV/AIDS and TB epidemic, burgeoning rates of non-communicable diseases (including mental illness), high levels of

⁶ According to the above definition, disability is not considered to be a characteristic of the person but of a situation or experience, giving rise to a preference within the South African disability community for the term "disabled people" over "people with disabilities" (Watermeyer et al. 2006). However, standard terminology proposed in the UNCRPD prefers the latter term (United Nations 2006), and the international phrasing will be adopted here for ease of reference.

⁷ From here on, where people with disabilities are mentioned, this is assumed to include their families.

violence and trauma, and the typical developing-country problems of maternal and child health and diarrhoeal disease (Mayosi et al. 2012). Although the GDP per capita spend on health is relatively high, health outcomes remain disproportionately low, and the bulk of spending occurs in the private sector (Naledi et al. 2011). Finally, the state health system has been beset by political, managerial and administrative failures, and a human resources crisis (Mayosi et al. 2012). Rural communities have been disproportionately affected by all of these issues (Gaede & Versteeg 2011). In response to these dire circumstances, the National Department of Health has adopted a programme of Re-engineering Primary Health Care, modelled on comprehensive principles and intended to achieve universal health coverage. This renders PHC philosophy particularly pertinent to HPSR in a South African context.

PHC shares with CBR the principles of empowered community engagement, appropriateness to local needs, a holistic vision of health and an intersectoral vision for action, informed by human rights and social justice. Within CBR, health is included as one of five key domains for action, and includes prevention, promotion, curative services, rehabilitation⁸ and access to assistive devices (World Health Organisation 2010). PHC offers an excellent fit to deliver these things within a CBR framework. Unfortunately in South Africa, ongoing developments in PHC have largely neglected to consider disability in their design and delivery, excluding many people with disabilities from the healthcare they need (Moodley & Ross 2015). Rehabilitation, including mental healthcare and assistive devices, continue to be poorly planned for, resourced and supported within the state sector (Sherry 2015; Visagie et al. 2013; Dayal 2010; Rural Mental Health Campaign 2015).

1.3.5. Rural people with disabilities

Rural people with disabilities were chosen as the study population both for my personal interest in this group, and because the compounding effects of rural poverty, environment and health service challenges render them vulnerable in ways that are not well understood. Almost half of the South African population lives in rural areas (Kok & Collinson 2006), and rural districts continue to show the highest poverty levels and poorest health indicators in the country (Massyn et al. 2015; Gaede & Eagar 2013). Rural health systems consistently suffer difficulties attracting and retaining staff, providing professional support and development, upgrading historically poor infrastructure, ensuring good governance and quality of services, coordinating care with other levels of the health service, and overcoming logistical constraints to service delivery (Versteeg et al. 2013). While these issues also affect urban services, rural districts are more seriously impacted, due to a historical lack of investment, inappropriate budgeting procedures, and local political and socio-economic factors (Gaede & Versteeg 2011; Eagar et al. 2015). Rural underdevelopment and poverty, particularly in the former homeland areas, contribute to poorer social determinants of health, and a higher burden of disease (Noble & Wright 2013; Gaede & Versteeg 2011).

At the same time, people with impairments or chronic illness in rural areas encounter multiple barriers to mobility, activities of daily living and social participation. Long distances, difficult terrain, lack of accessible transport and often lack of access to piped water, sanitation and electricity, render relatively minor impairments far more significant (Duncan & Watson 2009). Such barriers will also impact on access to healthcare. All of these factors give reason to believe rural people with disabilities to be an especially vulnerable population. To date, very little evidence exists about the nature and extent of this multidimensional disadvantage, or its relationship to chronic poverty in rural areas.

⁸ Note the distinction between rehabilitation as a component of healthcare, and CBR (see Definition of terms)

1.4. Research outline

1.4.1. Problem statement

Current health service provision for rural people with disabilities in South Africa is inaccessible, inadequate and inequitable, even in comparison with services for poor communities in general. PHC reforms and community engagement mechanisms do not seem to be making services more responsive to the challenges faced by this group, with potentially serious consequences for their health and development. There is not enough known about the interface between rural people with disabilities and PHC workers to inform appropriate interventions to address this problem.

1.4.2. Purpose

To contribute to theory on health system design and interventions which aim to promote equitable, effective and appropriate healthcare for rural people with disabilities, through the strengthening of citizen engagement in health.

1.4.3. Aim

To describe the interface between rural people with disabilities and PHC workers, in order to theorise how this could be strengthened to make health services more responsive and equitable

1.4.4. Research question

What is the nature of the engagement between rural people with disabilities and PHC workers, and what potential does this offer for more responsive and equitable health services?

1.4.5. Objectives

1. To describe the participatory spaces which make up the interface between villagers and healthcare workers
2. To describe the occupations taking place in and around these participatory spaces, both of rural villagers and healthcare workers
3. To interpret the engagement of rural people with disabilities with healthcare services in terms of the Primary Health Care principle of empowered community engagement in health
4. To theorise how this engagement could be strengthened for more responsive and equitable healthcare services

1.5. Core features of the study

This study adopted a qualitative, ethnographic lens to investigate the micro level interactions between eleven households, each including a member with a disability, and local PHC services in a small and remote village in Alfred Nzo district, in the Eastern Cape. The embedded case study took a narrative approach, following the participants over approximately eighteen months, and exploring in detail how people's engagement with healthcare unfolded through their daily occupations in and around the participatory spaces where they engaged with health services. Participants' stories were complemented by data generated through participant observation in these spaces, and discussions with healthcare workers.

The study offered particular cultural, linguistic and personal challenges, as I did not share a language, socio-economic or cultural background with most of the participants, and had limited insight into local cultural and social worlds. I was also therefore a highly conspicuous presence both in the village and in the health facilities. Essential to the feasibility and success of the project was the employment of a local man as interpreter, advisor, negotiator and ultimately co-researcher. Xakathile Dabula, a man in

his early forties resident in a location near to Kwabisi, had worked with researchers from the Division of Occupational Therapy at the University of Cape Town on two previous research projects involving people with disabilities in Kwabisi village. Prior to this, he had over ten years' experience as a research facilitator and implementer in the Eastern Cape and in Cape Town, working with both South African and international researchers from the fields of health, geography and economics, among others. I came to know Xaks⁹ (as he is generally known) during the second project (2010-2012), when I joined the team as an assistant researcher. It was during this study (described further below) that the inspiration and opportunity for my doctoral work arose.

1.6. The study site

I came to know the study site through involvement in prior research with occupational therapists from the University of Cape Town (UCT)¹⁰. Between 2006 and 2012, two research projects were conducted which addressed the experiences of people with disabilities and their households in the rural context. The first, called the Poverty, Disability and Occupation Study (PDO), investigated the complex dynamics between poverty, disability, and the things that people do every day, i.e. their occupations. The second, entitled "People influencing policy: power and progress" (known as PPP), was a participatory project addressing the implementation of disability rights and policy in people's access to local services, including health, education and social development. Both studies were funded by the South Africa Netherlands Partnership for Alternatives in Development (SANPAD), and form an important background to the current study.

Kwabisi location is situated in the north eastern corner of the Eastern Cape Province, in Alfred Nzo district, and forms part of the former homeland of Transkei. The location is a dispersed settlement of households organised in loose clusters under tribal leadership, and has a population of approximately 1500-2000 people, although as in other rural areas of South Africa, there is considerable migration to and from the cities for employment (DuToit & Neves 2007; Kok & Collinson 2006). Residents are mostly members of the Bhaca clan of the amaXhosa, who speak a dialect of isiXhosa (isiBhaca). Separated from the nearest tarred road by 20km of poorly maintained gravel road, residents travel 45km to access shops, banks and other services at the nearest town, which has a population of approximately 5000.

⁹ The "x" in the isiXhosa language is pronounced as a palatal click. An alternative pronunciation for non-isiXhosa speakers sounds like "Clucks".

¹⁰ The study site is located in the neighbouring district to the community where I worked as an occupational therapist from 2006-2011. Approximately 300km apart, the two areas both fall within the former Transkei and are similar in terrain, infrastructure, deprivation and health system challenges.



Figure 2: Kwabisi location

1.7. Summary

This study addresses the engagement between rural people with disabilities and PHC systems, in the light of their right to health and its intersection with issues of poverty and development. The current moment in South Africa's history is characterised by growing inequity between rich and poor, with black rural populations continuing to experience extreme deprivation and highly constrained access to health services. Within this group, people with disabilities are likely to be both overrepresented and under-recognised, with disability itself constituting a key mechanism through which poverty and inequity are perpetuated. Health systems research and policy have thus far neglected disability and rehabilitation as issues of public health, human rights and development.

Eleven in-depth case studies were carried out using qualitative ethnographic methods, to investigate how rural people with disabilities and their households engage in the participatory spaces of the PHC interface. Within a capabilities framework, an occupational perspective was employed to capture the complex micro-level dynamics of these spaces.

Chapter 2: Literature Review

2.1. Introduction

Little research has been done into the daily lives of rural people with disabilities in developing countries, including their engagement with healthcare services. While a small body of evidence is accumulating on people with disabilities' access to healthcare, none was found that considers their engagement within the interface between communities and health services more broadly.

Searches on CINAHL and Medline for peer-reviewed English-language publications from the past eight years, using the terms "disability" and "primary health care", yielded 94 and 505 articles respectively. Of these, CINAHL cited only one from a LMIC, and Medline, 17. Of these, the majority were impairment and/or intervention specific, and none directly addressed engagement between rural people with disabilities and PHC workers. Hand searches of specific journals, and of the reference lists of key articles, were used to extend the literature base of this chapter.

This chapter begins with a discussion of key concepts, including disability, health and poverty. I introduce the capability approach, which is adopted as the conceptual framework for the study. The second part of the chapter contextualises the study within health policy and systems research (HPSR), specifically primary health care (PHC). Core features of PHC are discussed and evidence relating to rural South Africa and people with disabilities is reviewed. Thirdly, the construct of occupation and the potential contributions of occupational science to the focus of study are presented. The chapter concludes by summarising the conceptual framework adopted for the study.

2.2. Disability

This section discusses conceptualisations of disability and health, and articulates the relationship between disability and healthcare. Sen's capability approach (Sen 1999) is introduced as a framework to define key concepts in the study, complementing the perspective on disability as a development and human rights issue. Dynamics linking disability and poverty in South Africa are reviewed, with particular reference to the rural setting. A need is identified for research into people with disabilities' experiences of healthcare in impoverished rural settings, in order to inform inclusive development strategies.

2.2.1. Conceptualising disability

Much has been written in the past few decades about the socially constructed nature of disability, acknowledging the social and structural forces that serve to exclude people from society (Officer & Groce 2009). This 'social model' of disability stands in contrast to the medical model, which sites disability in the person and their impairment, with the implication that the individual should adjust (or be adjusted) to the world, or be excluded (World Health Organisation 2011). The medical stance is strongly normative, with impairment seen as a problem to be fixed, or considered a failure of a body structure or function arising from a health condition. The medical way of thinking about disability and the service related needs of people with disability still prevails in the field of health.

The development of the International Classification of Functioning, Disability and health (ICF) by the WHO, has been particularly influential in bringing together the concerns of the health system (specifically preventing, reducing and remediating impairment) and those of the disability movement and human rights (World Health Organisation 2001; Jelsma 2009). Significantly, the ICF has also shifted the perspective on disability as a long-term or permanent condition, to a universal aspect of the

health/illness experience, across the lifespan (World Health Organisation 2011). Designed to offer a common language for describing the intersection of health conditions with function and participation, the ICF has been successfully used to demonstrate the disabling dimensions of priority health conditions, notably HIV/AIDS (Myezwa et al. 2011; Cobbing et al. 2014).

The ICF model describes three levels making up disability, namely body structures and functions (impairment level), activity limitation (functional level), and participation restrictions (impact of functioning on social inclusion and full membership of society). It recognises that disability arises from the interactions between impairment and a wide range of personal and environmental factors, so that the experience produced is unique to situation, and changes over time (see Figure 3). The role of social and environmental supports, personal capacities and the demands of different life situations, can thus be accounted for in both describing and addressing disability.

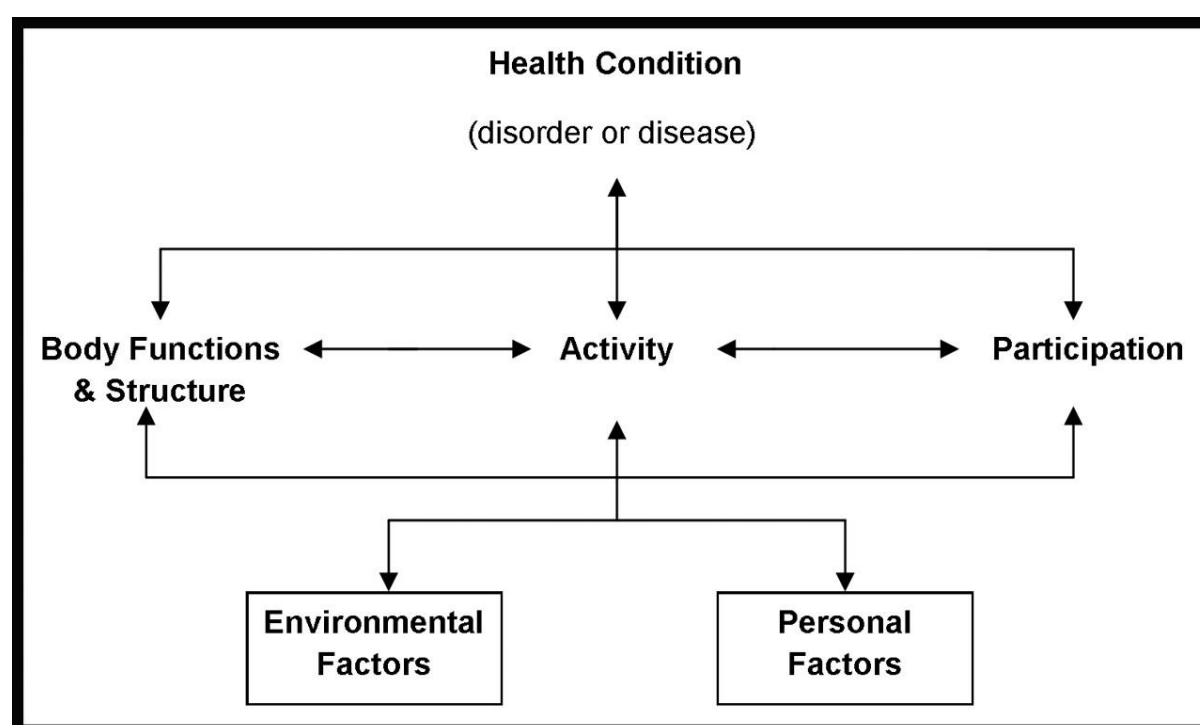


Figure 3: The ICF model of disability (WHO, 2011)

Experience around the globe in using the ICF for research purposes, has raised a number of issues for further development of the instrument, including absence of potentially useful codes, confusion in use between specific codes and also between activity and participation domains, and limitations to the standardisation of use across settings (Jelsma 2009). A more serious limitation, in the context of the study, is the lack of attention to the structural drivers of inequity and poverty, and the ways in which inequitable and deprived environments may produce impairments (Hammell, 2015). The ICF also remains focused on the individual, and does not address the ways in which disability affects the participation of family and community members, and vice versa (Trani et al. 2009). The intersection of social and personal factors such as gender, race, and socio-economic class with disability, is also inadequately captured, despite evidence to suggest that these intersectional features of human identity are significant in determining experiences of vulnerability and exclusion (Emmett, 2006; Neille & Penn, 2014). These and other limitations arising from the narrow conceptualisation of disability are significant in shaping engagement between people with disabilities and health services.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) draws on the ICF model, but acknowledges the contested and evolving nature of disability as a concept. It defines disability as “result[ing] from the interactions between persons with impairments, and attitudinal and environmental factors that hinder their full and effective participation in society on an equal basis with others” (United Nations 2006, Preamble). This definition will be adopted for the purposes of this study, alongside some further considerations pertaining to people with disabilities in rural South Africa. Disability is understood to be a multidimensional experience, which changes over time and context (World Health Organisation 2011). It may arise from a long-term impairment, but may also be the result of shorter term or episodic conditions, rendering it a dimension of the universal human experience, rather than the characteristic of a defined group (World Health Organisation 2001). At the same time, disability over the lifespan is understood to produce cumulative vulnerabilities and compounded disadvantage, which affect not only the individual but also her household and community (Duncan & Watson 2009; Groce et al. 2011; Trani et al. 2009).

Framing disability as a social, developmental and human rights issue shifts the focus of intervention from individualised biomedical treatment to a combination of personal and societal responses. Community-based rehabilitation (CBR) has been championed by the WHO as a rights-based, intersectoral approach aimed at social inclusion and the removal of barriers to people’s full participation as citizens in society (World Health Organisation 2010). CBR is envisaged as a comprehensive approach to inclusive development and poverty reduction, through locally appropriate activities across five areas, namely health, education, livelihoods, social and empowerment. While this study focuses on the health sector, it is important to note that healthcare is not considered solely responsible for addressing disability, and the extensive linkages between the five domains are acknowledged.

It will be noted that the CBR framework includes rehabilitation as a specific activity within healthcare. Rehabilitation in this sense refers to “a set of measures which enables people with disabilities to achieve and maintain optimal functioning in their environments” (World Health Organization 2010a, p8-9). This includes services provided across a range of contexts (from home and community to hospital), and through a range of providers, including rehabilitation professionals such as occupational therapists. In South Africa, the health sector is the primary provider of rehabilitation services, via public, private and non-governmental organisations.

2.2.2. Disability prevalence in South Africa

Given the complex and contextualised nature of disability, its measurement presents considerable challenges. Both nationally and internationally, differing approaches render comparison between regions and over time difficult, and produce widely varying estimates of prevalence for a given population. Historically, disability has been identified in survey and census instruments via diagnosis (i.e. presence of impairment), and self-identification as disabled. An impairment focus alone fails to account for the role of environment in either supporting or excluding participation, while self-identification is subject to personal perceptions of disability, and a range of social and cultural factors that may discourage people from adopting the label (Samman & Rodriguez-Takeuchi, 2013; Schneider, 2009). More recently, the Washington Group on Disability Statistics has introduced a set of six questions, based on the ICF model of disability, which capture the interaction of impairment and environment in producing actual levels of functioning (including mobility, vision and hearing, communication, cognition and self-care). This tool is being widely implemented in international and regional data collection, including in the South African Census 2011, which profiled people with

disabilities in South Africa in relation to a range of demographic characteristics, including age, gender, geographical location and racial group (Statistics South Africa 2014a). The report found an overall disability prevalence of 7,5%, although as it excluded children under five and people with psychosocial and some neurological disorders, this cannot be taken as conclusive. The exclusion of mental, neuropsychiatric and substance abuse (MNS) disorders from this census confirms the tendency of South African policy makers to interpret disability as a physical, biomedical phenomenon, something that can be observed as wrong with the external body.

An alternative estimate of disability prevalence in South Africa is drawn from the World Report on Disability (World Health Organisation 2011). The report acknowledges ongoing limitations in existing disability data, and compiles estimates from two sources, namely the World Health Survey (2002-4) and the Global Burden of Disease Survey (2004 update). The former includes ICF-based questions on functioning similar to those described above, while the latter uses Disability-Adjusted Life Years (DALY's) to estimate the burden of morbidity and mortality related to disease prevalence¹¹. The combined estimated prevalence of disability in South Africa is 24,2%, significantly higher than the global estimate of 15,3-15,6% (World Health Organisation 2011). This figure includes adults aged 18 years and older only and does address the MNS disorders. The wide variation between this figure and that yielded by Census 2011, indicates the uncertainties and complexities of measurement methodologies, and there is still considerable work to be done in producing comparable, accurate and comprehensive data on disability (Samman & Rodriguez-Takeuchi, 2013; Schneider, Dasappa, Khan, & Khan, 2009; World Health Organisation, 2011).

While precise figures are unknown, it can be assumed that numbers of people living with significant functional impairment are increasing in South Africa, as elsewhere in the world. The so-called quadruple burden of disease, spanning infectious diseases (specifically HIV and TB), maternal and child mortality, violence and trauma and non-communicable diseases of lifestyle, creates a formidable "shadow" of chronic illness and impairment, alongside successes in prolonging lives (Sherry 2015). The transition of HIV/AIDS from a terminal to a chronic illness, through the successful roll-out of HAART, has particular implications for disability in a population with one of the highest rates of infection in the world (Hanass-Hancock et al. 2013). The global pandemic of mental illness is also reflected in local burden of disease, with a twelve-month prevalence of 16,5% for all mental disorders, alongside evidence of multiple serious risk factors for mental illness in the population, including poverty, inequality and high levels of violence (Burns 2011; Lund 2014; Lund et al. 2011).

The burden of disease however speaks only to the impairment level of disability. The South African context offers further challenges in environmental terms, particularly for the large proportion of the population still living in poverty. While impairments dwell predominantly in the health domain, disabling environments span education, public spaces, basic services, livelihoods and social structures and dynamics, among others. Health services themselves may constitute disabling environments, both through their non-inclusive design, and through the medicalising conception of disability predominating within them. Existing measures of disability prevalence in South Africa fail to take

¹¹ DALY's attempt to create a standardised measure of the health impact of different conditions, by combining estimates of years of life lost due to an illness, with years lived with illness or disability. The resulting weightings are used to quantify the morbidity and mortality burden posed by a given disease, to inform resource allocation and service decisions. The measure has been extensively criticised for its failure to consider the role of context in determining actual ill health, mortality and disability experienced, and its attempt to separate health from well-being in context is argued by some to be artificial and unhelpful (Voigt & King 2014).

account of the wide variation in living environment of its citizens, and therefore are likely to miss the extent to which disability compounds other vulnerabilities in disadvantaged communities.

I have elsewhere argued the case for disability as a critical public health issue in South Africa, and for rehabilitation as an essential component of PHC (Sherry 2015). Despite the absence of quantitative data to describe the intersections of disability with priority health conditions (especially HIV and TB), there are compelling reasons to consider how disability may be affecting access to and retention in care. Rehabilitation, although often considered a separate activity within healthcare, in fact includes secondary and tertiary prevention as well as health promotion, and is uniquely equipped to interrupt the downward spiral of ill health and exclusion from healthcare when primary and secondary prevention of other kinds fails (Sherry 2015).

2.2.3. Conceptualising health

Understandings of health and illness hold important implications for how disability is understood, and for how health systems are conceptualised. While impairments are easily framed within a biomedical paradigm, the experience of disability as defined above, is not. Health systems tend to adopt a medical model view of disability, based on a conception of health itself that focuses on disease rather than broader well-being (Möller 2015). This leads to services which discount people with disabilities as ‘failures’ when they cannot be cured, and tend to exclude them from system design, planning and resource allocation (Shakespeare et al. 2009).

The WHO definition of health is commonly cited as the guiding concept for health systems, i.e. “a state of complete physical, mental and social well-being, and not merely the absence of disease or illness” (World Health Organisation 1978). This was a major step in its time in shifting thinking about health in a more holistic direction, and the ICF has built on this definition with its ‘biopsychosocial’ model (World Health Organisation 2001). At the same time, the definition is increasingly questioned (Huber et al. 2011; Horton 2009; Law & Widdows 2008). Firstly, it has proved difficult to operationalise for health system purposes, and the ‘complete state’ proposed is often an impossible goal in the presence of resource constraints and the broader socioeconomic and environmental challenges facing most societies. Secondly, it is argued that since the definition was created, the global burden of disease has shifted from predominantly infectious and acute conditions, to a higher rate of non-communicable diseases of lifestyle (Huber et al. 2011). Many people therefore live years of their lives with chronic disease, requiring an understanding of health that can accommodate well-being without a “complete” state of physical or mental health. The same is true of people with disabilities.

Other dimensions to health are also being considered today. The health of the environment, the sustainability of lifestyles, and harmony between human beings and the rest of the natural world, are receiving increasing attention (Alves & Rosa 2007; McMichael et al. 2006). Global warming and other indications of human impact on the ecosystem, have made us more aware of the interconnectedness of human and ecological survival and well-being, leading to an ecological and sustainability dimension being considered essential to human health.

Collective and ecological conceptions of health are also being drawn from indigenous knowledge systems, with Western dualisms and individualism increasingly called into question (Owusu-Ansah & Mji 2013). Spirituality and the integration of physical, mental, emotional and social aspects of being, are added. The Xhosa belief system, in common with other southern African Nguni cultures, conceptualises human beings as intrinsically interconnected and interdependent, with full humanity

being attained only through relationship with others, and filling one's place in the social whole¹² (Metz 2011; Cornell & van Marle 2005). The emphasis on social harmony includes both the living and the spirit world, particularly the ancestors, who are understood to play an active role in daily life. Displeasing the ancestors through improper social behaviour or the rupture of relationships, can result in physical, mental, emotional and socio-economic misfortune, including disease, mental illness and disability (Holland 2012). Because people's worldview has significant implications for how ill health and disability are addressed, there is a need to consider contrasting health beliefs, including indigenous knowledge systems, within the participatory spaces of the health system.

Within the Western academic discourse, a number of alternative definitions of health are being proposed. Huber, Knottnerus, Green et al (2011) suggest defining health as a person's ability to adapt to their circumstances, including the capacity to self-manage health needs such as chronic illness. While this viewpoint still locates the problem within the individual, it has the strength of accommodating ongoing differences in health between people as well as environmental and socio-political changes, and of placing human agency and capacity at its centre (Horton 2009). However, for adaptation to be considered successful, it is necessary to define the end toward which people should adapt. Huber and colleagues (2011) indicate subjective well-being and quality of life as desired outcomes, but neither address the problems of operationalisation in the WHO definition, nor do they indicate how health systems might support adaptation. Further, by focusing on the individual's capacity to adapt, this approach ignores the structural inequities and social determinants which give rise to illness and exclude people from opportunities through which they can develop their potential. The implication is that the person must change, not the environment, paralleling the medical model of disability.

The Ottawa Charter for Health Promotion (1986) also called for supporting people to adapt to changing environments, but emphasised action on the social determinants of health, including public policy, the environment, sustainability, social justice and equity. The Charter conceptualises health in positive terms, as a resource for living rather than an end in itself, and calls for health systems to expand beyond curative and preventive activities to include active promotion of health. Despite this initiative, health research and interventions since then have continued to focus on countering pathology rather than strengthening health as a positive phenomenon.

More recently, Gunderson and Cochrane (2012) trace several promising developments in this direction, taking the position that "causes of life" should be investigated with the same rigor and interest as causes of death. The Leading Causes of Life framework, which builds on these various initiatives, posits five "causes of life", which can be linked to human flourishing in communities: coherence (the belief that life is ordered, manageable and meaningful) connection (social networks and belonging), agency, intergenerativity (connection and continuity between generations) and hope (Gunderson & Cochrane 2012). Related empirical work has highlighted the power of social and relational dimensions of health systems and communities, including work on Congregational Health Networks (CHN's), an initiative drawing on religious social assets to strengthen access to healthcare.

This represents an important shift from perceiving health systems as 'delivery' mechanisms for biomedical interventions, to understanding healthcare as a set of social and relational processes which themselves form part of health generation and promotion. Health outcomes are understood not as the absence of disease or a return to certain parameters of physiological functioning, but as the

¹² This philosophy is most widely known as *Ubuntu*, and is summed up in the proverb "*Umuntu ngumuntu ngabantu*": a person is a person through other people.

positive ability to live a life of value. This relates strongly to the idea of health as conceptualised in capability terms.

2.2.4. The capability approach: disability and development

The alternative definitions of health discussed thus far share the understanding that health may mean different things to people in different circumstances and settings. They also foreground human agency in the genesis and maintenance of health. A natural consequence of both propositions is that people themselves are responsible for defining their health needs at any given point, and potentially making trade-offs between aspects of physical, mental, social and spiritual well-being. This is taken further by the capability approach, first developed by Amartya Sen (Sen 1999), which defines the ends of human development as the range of things that people are able to do and be, rather than the attainment of a particular level of income or primary goods. The doing and being themselves are termed functionings, while the various possible functionings available to people in a given context are termed capabilities. The distinction between the two is underpinned by Sen's emphasis on freedom: not only should people have their needs met (opportunity freedom), but they should be able to choose between possibilities (process freedom). Capability scholars argue that the capabilities construct more closely approximates what people themselves value and strive for, than conventional economic measures of development (e.g. GDP per capita), or indeed health (Deneulin & Shahani 2009).

A capabilities definition of health acknowledges 'elementary' health functionings, such as being well nourished or free from pain, but also includes more complex functionings, for example being able to participate in community life or fulfil family roles (Ariana & Naveed 2009). The specific combination of capabilities chosen will depend on personal factors, social and cultural norms and beliefs, and the particular options possible with available resources. An important distinction is made between resources for health and realised capabilities, as it is recognised that different people may have different capacities to convert resources into functionings. Sen's examples include the diverse nutritional needs of children, pregnant women and the elderly, and the differential resource needs created by disability. These various characteristics are termed conversion factors (Sen 1999).

Based on his commitment to personal choice and agency, Sen resisted defining a core set of essential capabilities, although other scholars (notably Martha Nussbaum) have attempted this (Nussbaum 2006). An important strength of the approach therefore is its potential to be adapted to different cultural and social contexts, and to diverse individuals, with minimal imposition of normative values (Alkire & Deneulin, 2009; Hammell, 2015; Law & Widdows, 2008). At the same time, agreement on a core set of priority human capabilities is argued as a necessary basis for human rights and social justice (Venkatapuram 2007). This study recognises both the shared rights to such basic capabilities (e.g. bodily integrity, human dignity), and the role of personal freedom in defining what specific capabilities constitute optimal health in a given situation. Biomedical health services, focused on the impairment level of body structures and functions, tend to define health in terms of elementary capabilities, such as freedom from pain and disease, and the ability to perform basic functions such as walking. Rehabilitation (particularly occupational therapy), embraces a more comprehensive understanding of health, addressing what people are able to be and to do in context, and in line with valued goals (Hammell 2015). By adopting a capabilities definition of health for this study, we align health with both the participation level of the ICF, and with the construct of meaningful occupation, which will be discussed further in the third section of this chapter.

2.2.5. Disability and healthcare services

The World Report on Disability (World Health Organisation 2011) defines several types of relationship between health conditions and disability. A person with a disability is not necessarily ill, even where impairment is permanent. However, a person with a disability may have the same general healthcare needs as others, as well as the condition giving rise to the impairment. This is termed the primary condition (e.g. hypertension leading to stroke). Secondary conditions arise from complications related to the impairment (for example, pressure sores in people with spinal cord injury), while co-morbid conditions exist alongside and have potential links to the primary condition (World Health Organisation 2011). People with disabilities therefore require access both to the same general healthcare as the population at large, as well as to disability-specific services. As mentioned previously, health constitutes one of the five domains of CBR, and includes health promotion, prevention, curative services, rehabilitation and access to assistive devices (World Health Organisation 2010). Comprehensive health services are envisaged as a critical element of, and contributor towards, social inclusion and equal opportunities for people with disability.

There is strong reason to believe that people with disabilities are more vulnerable to becoming ill than people without. Disability may expose people differentially to health risk factors, such as poor access to clean water and sanitation (Noga & Wolbring 2012), exclusion from education (Mitra et al. 2013; Human Rights Watch 2015) and multidimensional poverty (Mitra et al. 2013; Eide & Ingstad 2013). People with disabilities may have less access to healthcare, both preventive and curative (Chevarley et al. 2006; Smith et al. 2004; Hanass-Hancock et al. 2013; Rohleder et al. 2009; Mesidor et al. 2011). There is some evidence that even when these factors are controlled for, the risk of certain diseases is higher for certain groups of people with disabilities than for others (Sartorius 2007).

Evidence from South Africa on the health needs and access to healthcare of people with disabilities is very limited (Moodley & Ross 2015; Maart & Jelsma 2014). A recent study utilising data from the National Income Dynamic Survey (NIDS), found that people with disabilities on average reported poorer health status, more frequent utilisation of healthcare, and higher rates of unmet need. They were also more likely to have certain communicable and non-communicable diseases (both related and non-related to their disability). People with disabilities were less likely than their non-disabled peers to have medical insurance, and were therefore more often reliant on the overstretched public health system (Moodley & Ross 2015).

Further research describes a number of common barriers facing people with disabilities in accessing healthcare, including transport, inaccessible facilities, financial costs of access, healthcare workers attitudes and lack of skills and knowledge regarding disability, and the fragmentation and lack of continuity within the healthcare system (Grut et al. 2012; Swartz et al. 2011). While many of these issues are also experienced by non-disabled South Africans, there is reason to believe that people with disabilities are more seriously affected by them. Unfortunately, evidence regarding the differential impacts of such conditions in the South African context is lacking. International research indicates that people with disabilities experience poorer access to general healthcare than their peers, including routine preventive care, reproductive healthcare, and the coordination of care for multiple and complex needs (Chevarley et al. 2006; Smith et al. 2004; Drainoni et al. 2006; VanRooy, E. M. Amadhila, et al. 2012; Swartz et al. 2011; McColl et al. 2008).

A particular concern, both locally and internationally, is the limited availability of disability-specific services, including rehabilitation and access to assistive devices. A study by Maart and Jelsma (2014), which interviewed households in a peri-urban area of Cape Town, identified the greatest unmet healthcare needs related to home-based care, rehabilitation and access to assistive devices. This is

echoed in a study on access to rehabilitation services for children with disabilities in another peri-urban area, which found that only 26% of the participants needing rehabilitation had access to it, with physically impaired children being far more likely to receive help than those with psychosocial impairments (Saloojee et al. 2007). Burns (2011) describes the serious treatment gap for people with mental illness in South Africa, while Mkhize and Kometsi (2008) describe the failure to implement comprehensive psychosocial healthcare at PHC level, due to the biomedical orientation of the existing health system, resource constraints, and shortfalls in staffing, leadership and management. The situation is especially dire for people with mental illness living in rural areas (Rural Mental Health Campaign 2015). No data is available on the coverage of rehabilitation services in rural areas in South Africa.

This brief review establishes people with disabilities as a vulnerable population with regards to healthcare, experiencing both increased health risks and needs, and simultaneously reduced access to services. The dearth of research on the health and healthcare access of people with disabilities in South Africa confirms the relevance of this study.

2.2.6. Disability and poverty

Disability has been framed as a development issue, with strong links to health. We turn now to examine the relationships between disability and poverty in the South African context.

The understanding of poverty has developed significantly over the past two decades, from a primarily income-related concept, to a multidimensional experience of exclusion and deprivation. The Voices of the Poor study, led by the World Bank, captured the experiences of poor people across the globe, and identified not only exclusion from opportunities in education, livelihoods, and socio-cultural activities, but also a prevailing experience of lacking voice and power in the institutions that determine the lives of poor citizens (Narayan, Patel, et al. 2000; Narayan, Chambers, et al. 2000). This shift in thinking corresponded with the development of the capabilities approach to human development (Sen 1999; Deneulin & Shahani 2009). A complex and contested concept, poverty remains difficult to measure, rendering research into disability and poverty doubly challenging.

The bi-directional relationship between disability and poverty is widely acknowledged, although definitive quantitative data describing this relationship remain scarce (Braithwaite & Mont 2009; Mitra et al. 2013; Yeo & Moore 2003). Circumstances of poverty expose people to multiple risks for impairment, and often exclude them from health interventions that might prevent or reduce ongoing ill health and disability. Poor people's environments offer fewer resources for adapting to impairment, including less choice about living environments, less access to assistive devices and technology, and little voice or power to challenge societal barriers (Elwan 1999; Dubois & Trani 2009; Groce et al. 2011). At the same time, people with disabilities are more likely to become and remain poor. Children with disabilities in most countries are less likely to access education, and a recent Human Rights Watch report revealed that in South Africa, half a million children with disabilities are excluded from basic education (Human Rights Watch 2015). This feeds into a high unemployment rate among adults with disabilities, exacerbated by barriers in the workplace (Loeb et al. 2008; Mitra 2008). Pertinent to this study is the restriction in life choices and opportunities available to rural people with disabilities, and the influence this has on their health and healthcare seeking.

The presence of a family member with a disability has also been shown to have multi-faceted ramifications for the livelihoods and opportunities of the whole household (Duncan et al. 2011b; Groce et al. 2011), with such households being over-represented among the chronically and multi-

dimensionally poor (Aliber 2003; Mitra et al. 2013). The costs of ongoing complex healthcare needs over time renders people with disabilities particularly vulnerable to the medical poverty trap (McIntyre et al. 2006; Whitehead et al. 2001), and potentially restricts healthcare seeking by other household members due to exhausted resources (Duncan et al. 2011a; Altman et al. 1999).

Data on disability and poverty are scarce for South Africa, as for most LMIC's. A cross-sectional study comparing living conditions between households with a disabled member and those without, found that people with disabilities consistently had lower educational attainments and employment levels than their peers, although in one site where employment rates were extremely low (6%), no difference in this specific measure was found (Loeb et al. 2008). These findings reflected those in similar assessments of poverty-disability relationships across the southern African region (Eide & Ingstad 2013).

Unique within the region is the existence of a South African government disability grant ('DG'). Equivalent to US\$80 per month (R1270), the grant is means-tested, and awarded to people with disabilities over the age of 18 considered unable to work due to their impairment (South African Social Security Agency 2015). In poor rural communities, social welfare grants, including the DG, are often the primary source of household income, with 36,6% of people in the study district receiving grants in 2011 (Alfred Nzo District Municipality 2015). In the study by Loeb et al (2008) described above, rural households with a disabled member actually reported a higher mean monthly income than those without, and also had a larger number of key possessions, than their neighbours. While this points to a general poverty alleviation effect, the grant did not seem to improve access to services for people living with disabilities. Not only is the amount inadequate to offset the actual costs of living with a disability, but where no other household income is available, the grant is commonly used for the needs of the whole household (MacGregor, 2005; Neille & Penn, 2015). Healthcare workers responsible for assessing and making recommendations about grant eligibility, face complex decisions, needing to weigh the official rules against the realities of poverty and high unemployment across the board in many communities (Swartz & Schneider 2006). Understandably, large numbers of people present to clinics and hospitals with the specific intention of negotiating a grant, often producing negative attitudes among health workers towards those seen as abusing the system (MacGregor 2005). These dynamics have significant implications for the engagement between people with disabilities and healthcare workers at the study site.

It is important to note that South Africa as a whole experiences a high unemployment rate (Statistics South Africa 2015), and that the mainstream state education system is widely considered to be failing even learners without disabilities (Spaull 2015; Wilkinson 2015). While there is unquestionably an urgent need to address the challenges faced by the general population, it is critical that efforts explicitly include people with disabilities from the outset. International evidence suggests that this group tends to remain consistently disadvantaged even relative to other disadvantaged populations, and that the gap tends to become greater in middle-income countries, suggesting that people with disabilities may be systematically excluded from development efforts, and are therefore left behind as the general population experiences improvements in living conditions and life opportunities (Mitra et al. 2013; Yeo & Moore 2003).

2.2.7. Disability and rurality

There is no clear agreement on the definition of rurality in South Africa, although the term 'rural' is used widely in government policy and rhetoric (Gaede & Versteeg 2011). Factors commonly included in rural definitions in the literature include population density, geographical isolation, deprivation and prevalence of agricultural livelihoods (Bourke et al. 2012). Couper (2003) points out that definitions

are shaped by the purposes they serve, and rural definitions for health purposes tend to highlight healthcare worker to population ratios, access to referral services such as medical specialists and ease of evacuating a patient in critical condition. Muula (2007) argues that a universal definition is impossible, due to the heterogeneity of areas referred to as rural, and proposes that researchers instead describe the characteristics of the study location to clarify how the term is applied.

Statistics South Africa classifies provinces and districts as (predominantly) rural or urban based on a combination of characteristics, including access to amenities and infrastructure, presence of traditional leadership structures and being situated outside classified metropolitan areas (Kok & Collinson 2006). These definitions are useful in comparing health systems functioning and outcomes in urban and rural areas (e.g. Massyn et al. 2015), but there remains considerable variation in conditions between different rural areas, indicating the need for caution in interpreting such relationships. Deprivation is known to be correlated with rural location, and this is most striking for the previous homeland or Bantustan areas.

Homelands were regions designated by the Apartheid government in 1951 as part of the racialisation of land ownership and residence laws. Predominantly rural with little economic activity or potential, homeland areas were allocated to black people groups, who were subsequently barred from owning land or residing in other parts of the country. The homelands policy purported to be preparing black people for self-government within independent nation states, but in practice served the needs of industry, particularly mining, for large reservoirs of cheap labour (Beinart 2001; Bank & Minkley 2005). Today, former homelands continue to face large backlogs in infrastructure and services, including roads, water and sanitation and electricity, and remain significantly more deprived than other parts of South Africa (Noble & Wright 2013).

These areas also continue to incorporate traditional authorities in local government, and are subject to land laws based on communal ownership. Traditional African belief systems and ways of life are more consistently practiced, although patterns of labour migration to urban areas for work (Kok & Collinson 2006), mean that 'tradition' and 'modernity' cannot be simplistically mapped on a geospatial basis.

The history and continuation of labour migration has a number of other important implications for rural areas. Firstly, the migrant labour system of the Apartheid period had a devastating effect on social structures, and the fragility of families and social relationships has been exacerbated by the HIV/AIDS epidemic (Coovadia et al. 2009). Within a relational African conception of health, this has had serious implications for communities beyond biomedical disease. Given this history, assumptions about the cohesion and social resources often associated with traditional rural areas must be considered with caution. At the study site, a large proportion of households are supported by breadwinners living and working in cities, only returning once a year, or for illness or a family funeral. As a result, many households are female-headed, and mainly comprise those who are too young, old or otherwise unable to seek work. This results in a high local dependency ratio (Alfred Nzo District Municipality 2015), as well as the likelihood of higher-than-usual rates of disabling illness or impairment, although little research exists to demonstrate this.

Health services in rural areas experience a range of specific challenges, including those common to rural and remote healthcare internationally, and locally specific issues. The former include difficulty attracting and retaining staff, remoteness from professional support and referral services, population access issues, and logistical challenges such as drug supply (Bourke et al. 2012). Locally specific concerns include lack of managerial and administrative capacity, accountability and transparency in local government, deficits in key social determinants of health through deprivation, and socio-political

dynamics (Gaede & Versteeg 2011). Challenges with accessing adequate health services increase the likelihood that rural dwellers will develop chronic illness and impairments, and decrease the chance that they will be afforded the support and services they require. The rural environment offers substantial physical barriers to mobility and functioning, with difficult terrain, long distances to amenities, lack of accessible transport and absence of services such as piped water and electricity. The complex socio-economic and cultural environment further adds to the likelihood that impairments will result in activity limitation and participation restriction (Duncan & Watson 2009).

Alfred Nzo district, within which the study took place, falls within the former Transkei homeland, which now makes up part of the Eastern Cape Province. According to the most recent census data, it is the most deprived district in South Africa (Gaede & Eagar 2013). Statistics from the national Community Survey 2007 (Statistics South Africa 2010) indicate that 81.1% of people in the area live below the poverty line (defined within the survey as earning less than R800 [US\$50,50] per month). Unemployment stands at 78.2%, with upwards of 30% of people being dependent on government grants (mainly child support grants and old age pensions). Subsistence farming is the predominant economic activity, and low formal employment is linked both to economic underdevelopment in the area, and low education and skill levels. Only 8.2% of the 5.5% who complete Grade 12 (senior school) have a tertiary qualification, while 11.9% have no schooling at all (Statistics South Africa 2010). Bank and Minkley (2005) suggest that Government is adopting a “welfarist” approach to such undeveloped regions, rather than exerting more effort in developing economic sustainability. Negative attitudes are seen to prevail, that perceive “the former homelands ...as zones of irretrievably damaged and ‘wasted’ land, with little scope and possibility for economic transformation” (Bank & Minkley 2005, p33).

Although including a handful of small towns along the national road passing through the district, the area is characterised by dispersed settlements made up of traditional homesteads, which house approximately 76% of the local population. These typically comprise two to four dwellings built using homemade mud bricks and thatched or corrugated iron roofing, which require regular maintenance and repair, especially during the heavy summer rainstorms. 75% of households do not have access to electricity. There is a massive backlog in water and sanitation service provision, and 20.7% of households have no toilet at all (Alfred Nzo District Municipality 2015). Roads are few and poorly designed and maintained, and although public transport functions along main routes, many rural areas have extremely limited access to this service. In summary, Kwabisi falls in an area of gross underdevelopment coupled with entrenched poverty, characteristic (although perhaps a more extreme example) of the rural former “homelands” of South Africa.

2.2.8. Summary

Disability is understood as a complex experience, embedded in the physical, socio-economic and cultural realities of the rural South African context. Evidence suggests intersections with priority health conditions, poverty and rurality, with significant implications for rural development and health systems. The capabilities approach is adopted as a framework within which the relationships between health, disability, poverty and the overarching development context can be understood. This review of the literature established the need for further research to understand how these relationships unfold at the micro level, within the daily lives of rural people with disabilities.

2.3. Health systems

2.3.1. Introduction

Health systems are defined broadly as “all the activities whose primary purpose is to promote, restore and/or maintain health” (World Health Organization, 2007). This definition is taken to include all the various service providers that may exist in a given setting, aspects of their structural organisation, such as financing mechanisms, medical technology and governance, and also the institutional, legal and policy frameworks by which they are governed. The way in which health itself is conceptualised shapes how health systems are thought about. Understanding health as capability, with a social and relational dimension that may be strengthened or fractured through the healthcare seeking process, leads us to reconsider dominant perceptions of health systems as mechanisms for delivery of health technologies. Health systems are increasingly acknowledged to form part of the fabric of society, embedded in a social and political context and having societal significance beyond their immediate functions (Gilson, 2003; WHO, 2015). The communities who use health services are therefore often considered an active part of the system, with various roles in shaping, sustaining and interacting with them (Sheikh et al., 2014). Health systems are inherently complex, and are sensitive to local realities as well as trends and shifts at national and international levels (Peters 2014; McPake et al. 2006; Adam 2014; Sheikh et al. 2014).

Health systems are taken to serve the core purpose of realising citizens’ right to health. Health itself is a precondition for access to other rights, such as education, work, and social and political participation. Health systems play an important role in achieving equity in the distribution of resources and opportunities for health (Cleary, Mooney, & McIntyre, 2011; Eide, Mutamad, MacLachlan, Mannan, & Schneider, 2013; Gilson, Doherty, Loewenson, & Francis, 2007). They have the potential to offer social and financial risk protection, through the cross-subsidisation of the poorer and more ill, by the wealthier and more well (Gilson et al. 2007), as well as to respond to the specific needs and circumstances of marginalised or at-risk groups, including people with disabilities (Amin et al. 2011; Eide et al. 2013; Schneider et al. 2013; Hanass-Hancock et al. 2011). The concern for equity has given rise to renewed local and international interest in universal health coverage, i.e. access for all citizens to adequate healthcare when they need it, without the risk of financial hardship as a result (Kutzin & Sparkes 2016; World Health Organization 2010b; World Health Organization 2013). While universal health coverage refers mainly to the financial aspects of realising the right to healthcare for all, primary health care is the philosophy of health system organisation through which this may best be achieved. PHC philosophy provides a framework for socially embedded and responsive health systems, which have the potential to better meet the needs of people with disabilities, especially in rural areas. While growing evidence exists for the impact of the relational features of PHC on healthcare access, effectiveness, efficiency and satisfaction for the population at large (World Health Organisation 2008a), there is a dearth of research on their relevance for people with disabilities in rural settings.

Access to healthcare has gained prominence as a policy concept in concert with the above concerns (McIntyre et al. 2009). Although access is often understood simply in physical terms of the availability of services (for example distance to nearest clinic, healthcare worker to population ratios), it is a complex and multi-dimensional concept, and the way it is understood has important implications for the design of health services. The relative access experienced by different groups, particularly of vulnerable people such as rural dwellers and people with disabilities, is a critical issue for health equity (Eide et al. 2013; Gaede & Versteeg 2011), and is determined by ‘degree of fit’ between healthcare seekers and health systems in context (Penchansky & Thomas 1981; McIntyre et al. 2009).

Understanding this fit requires micro-level investigation into the complex factors and relationships at play in the interface between communities and health services. For health systems to achieve and maintain this fit with the unique, diverse and dynamic communities in which they are situated, engagement in this interface must offer opportunities for voices of healthcare seekers to be heard, and for healthcare workers to respond in the ways they offer services.

The term ‘responsiveness’ has a specific association in the HPSR literature with so-called non-clinical features of service user experiences (Valentine et al. 2003; Entwistle et al. 2012). However, literal definitions of the word include “making a positive and quick reaction to something or someone” (Cambridge Dictionaries Online 2015), and “the ability of a machine to adjust quickly to suddenly altered external conditions... and to resume stable operation without undue delay” (Dictionary.com 2015). Both of these definitions reflect the interaction between system and context, which inherently includes local specificity. This meaning of the term is not entirely captured in the narrower usage in HPSR. The ability of health services to listen and respond to local needs is fundamental to PHC, both in interactions with individuals, and with the broader community (Sheikh et al. 2014). For the purposes of this study therefore, the term responsiveness will be used in its broader sense, to describe the property of a health service of being receptive and responsive to the range of needs, preferences and capacities of its community (Cleary et al. 2013; Molyneux et al. 2012).

Health systems may be studied at various levels, from the macro level where policies are made and overall approaches to financing and delivery models determined, to the micro level where healthcare reaches (or doesn’t reach) the people for whom it is intended. This study focuses on the latter, i.e. on the interface between communities and PHC services. The significance of micro-level dynamics in determining the nature of services and the implementation of policy has been widely recognised (Walt & Gilson 1994; Gilson & Raphaely 2008; Gilson et al. 2014). Frontline workers and healthcare seekers exercise agency and creativity in interpreting and adapting healthcare planning to the realities of service delivery, including their own interests and constraints, and this results in a policy implementation process that is ‘bottom-up’ rather than ‘top down’ (Erasmus et al. 2014; Gilson et al. 2006; Walt & Gilson 1994). A body of recent research explores this activity through in-depth case studies applying a range of social science lenses (Erasmus et al., 2014; Gilson & Raphaely, 2008; Gilson, Schneider, & Orgill, 2014). To date, the bottom-up policy implementation process as it pertains to people with disabilities, in particular rural citizens, has received scant attention.

2.3.2. Primary health care: international developments

Primary health care was first articulated as a coherent philosophy in the Declaration of Alma Ata (World Health Organisation 1978). Based on the human right to health and the need to address health inequities both within and between nations, PHC was described as “essential health care based on practical, scientifically sound and socially acceptable methods and technology, made universally accessible... as close as possible to where people live and work” (World Health Organisation 1978, p2). Healthcare was to be effective, efficient and comprehensive, including health promotion, prevention, curative care and rehabilitation, and services were to be tailored to address local health priorities. These priorities, as well as the general organisation, management and governance of services, were to be determined through the active participation of the communities who used them. Affordability and sustainability were considered key.

The implementation of this vision has varied widely across countries and over time. The comprehensive vision of Alma Ata was replaced soon after its promulgation by a narrowed focus on delivering specific technical solutions to a restricted set of priority health problems, most notably

maternal and child health, with interventions including growth monitoring, oral rehydration therapy and family planning (Parvin 2013; Bhatia & Rifkin 2013). Known as selective PHC, this approach arose from the belief among governments and international agencies that the original PHC vision was unrealistic and impracticable. Selective PHC coincided with the rise of neoliberal economic policy and structural adjustment programs in many countries, influenced by the World Bank, which called for the restriction of government spending, including on health (Bhatia & Rifkin 2013). During the 1990's, this approach began to be questioned in its turn, and by the mid 2000's, global attention had returned to the social determinants of health, and the need for strengthening health systems over implementing disease-specific vertical programs (Gilson et al. 2007; World Health Organisation 2007). In 2008, the World Health Organisation called for a revitalisation of PHC in its comprehensive form, as the answer to a new set of global health and health system challenges (World Health Organisation 2008b). While health issues of poverty, particularly infectious diseases, had been addressed with some success following Alma Ata, the real health of populations had largely failed to benefit proportionately from the scientific advances in medical treatment. Comprehensive, rights-based PHC was proposed anew as the path to stronger health systems (Bhatia & Rifkin 2013; Walley et al. 2008), and further integrated into the recent call for People-centred Health Systems (PCHS) (World Health Organization 2015b).

2.3.3. People centred health systems

People Centred Health Systems (PCHS) is an emerging construct within HPSR, which calls for a reorganisation of healthcare around “people not diseases”, based on local needs and preferences, and incorporating the voices of communities whom health services serve (Sheikh et al. 2014; World Health Organization 2015b). It is linked to an increasing understanding of health systems as human and relational systems, not merely mechanisms for ‘delivery’ of interventions packages (Gilson 2003; Sheikh et al. 2014; Gilson 2005). Key features include integration and coordination of services, a holistic understanding of health in context, and values of human rights, dignity and social justice. No one set of health system arrangements is proposed, but PCHS claims to draw on a range of previously developed concepts and strategies, including person-centred care, action on non-communicable diseases, universal health coverage, action on social determinants of health, and PHC (World Health Organization 2015b).

While the call of PCHS for a reorientation of health systems based on the above principles is welcome, its conceptual basis is not yet well developed. The recently released WHO Strategy on PCHS (World Health Organization 2015b) offers the broad outline presented here, but does not explore why previous strategies along similar lines (most notably PHC) have failed to be implemented or to achieve their goals. While avoiding commitment to specific measures, the report claims a broad range of ‘benefits’ to PCHS, many of which may be mutually incompatible, for example reduction in healthcare costs and increased comprehensiveness of services available. An accompanying report reviews existing ‘evidence’ on PCHS (World Health Organization 2015a), but without an operational definition of the concept this is problematic, as is the adoption of the ‘hierarchy of evidence’ that privileges highly reductive, context-eliminated randomised control trials as the gold standard for quality.

This research study is contextualised within the global shift represented by PCHS, and aligns with the values of holistically defined health, human rights, social embeddedness and giving primacy to the voices of communities. It offers potential to work out some of these ideas in the context of people with disabilities living in impoverished rural settings.

2.3.4. PHC in South Africa

In South Africa, PHC has been championed by successive policy actors since the early twentieth century, as a key strategy to address the extreme inequities and widespread poverty of the population (Phillips 2014; Coovadia et al. 2009). The country's colonial history, followed by racialized self-rule culminating in Apartheid between 1948 and 1994, has resulted in a legacy of health and socio-economic inequities along racial, gender and geographic lines, which continues to the present day (Coovadia et al. 2009; Gaede & Eagar 2013; Massyn et al. 2015). At the transition to democracy in 1994, the health system was fragmented, hospicentric and heavily skewed towards urban areas (Naledi et al. 2011). While the early policies of the new regime reflected PHC principles, it was only in 2009 that decisive steps began to be taken towards thorough health system transformation, first with the Minister for Health's Ten Point Plan (Department of Health 2009), and thereafter with the plan to achieve universal health coverage through a National Health Insurance and the Re-engineering of Primary Health Care (PHCR)¹³ (Department of Health 2011; Naledi et al. 2011). At the time of writing, the pilot phase of these reforms is still underway, and a White Paper on a National Health Insurance had just been released for comment.

PHCR offers significant opportunities for improving access to healthcare and rehabilitation for people with disabilities, especially in rural communities in South Africa, and thus for fulfilling the state's commitment to the UNCRPD. Unfortunately, disability concerns have been all but excluded from the system transformation, and a consultative process to develop a disability and rehabilitation strategy for the health sector has been disappointingly ineffectual (Sherry 2015). Guidelines and protocols developed for PHC largely omit impairment screening and referral, even for obviously disabling conditions such as stroke. Where screening is required, for example in the paediatric Road to Health Chart and by school health teams, no provision is made for referral to appropriate rehabilitation teams (Sherry 2015). At the time of writing, the Framework and Strategy for Disability and Rehabilitation Services (2015-2020) was about to be adopted (Department of Health 2015), the final version reflecting a narrow, medical view of disability, in contradiction to extensive comment by the disability and rehabilitation sector.

This neglect of disability concerns in local health policy is reflected at international level. Despite the wide acknowledgement of the growing burden of non-communicable diseases and mental illness, and the increased years of life lived with illness and disability (Beaglehole et al. 2011; Whiteford et al. 2013; Mayosi et al. 2012), international policy shifts largely failed to include disability considerations. (Eide et al. 2013; Schneider et al. 2013). Although rehabilitation is routinely mentioned as part of comprehensive healthcare in international and national policy documents, it is seldom elaborated upon. Nonetheless, PHC clearly shares core principles with CBR, including a human rights base, a holistic view of health, an intersectoral approach and the active engagement of communities. Embeddedness in context and responsiveness to local needs and priorities are also key. This study is based on the understanding that disability is a critical dimension of health within development, which a comprehensive PHC approach is well positioned to address.

2.3.5. Core features of PHC systems

International proposals for renewing PHC as the basis for health systems included a set of core features of service organisation which offer a promising basis for a relational health system. These include closeness to communities, person-centred care, a known healthcare worker as regular point of entry to the system and the PHC team as the basis for continuity of care. Communities have also

¹³ Key features of PHCR are the establishment of nurse-led ward-based outreach teams (WBOT's), district clinical specialist teams and a school health program.

been attributed an essential role in health service policy, design, governance and delivery. These concepts will be discussed briefly below, and considered in relation to PHCR in South Africa, and to rural people with disabilities in this context.

2.3.5.1. *Person centred care*

Person-centred care is an approach to personal healthcare that foregrounds the relationship between healthcare worker and healthcare seeker. Patients and their families are accorded an active role in healthcare planning and decision-making, and are understood by healthcare workers in holistic terms, with attention to their values, beliefs and life context. This necessarily occurs within a positive and bi-directional relationship between healthcare worker and patient, characterised by respect and good communication. The care that results can be responsive to their needs, wishes and priorities, and take account of their specific circumstances (Kitson et al. 2013). Person-centred care has been called “the clinical method of participatory democracy” (Marincowitz and Fehrson, 1998 in World Health Organisation 2008a, p46), and there is evidence to suggest that it has a significant impact on both healthcare effectiveness and patient satisfaction (Olsson et al. 2013).

Person-centredness is a core concept within CBR and rehabilitation (World Health Organisation 2010; Hammell 2013), and is particularly important in healthcare for people with disabilities. The unique and embedded nature of disability requires healthcare workers to take account of personal and contextual dynamics in producing or preventing health. At the same time, CBR calls for the autonomy and choices of people with disabilities to be supported and enabled, so that they gain and maintain freedom to live the lives they choose.

In the South African public health system, person-centred care is aspired to in policy, but does not seem to prevail in practice. A study of rural healthcare workers’ experiences showed that the practice of person-centred care was constrained by under-staffing (leading to limited time and energy for each patient), lack of training and lack of supervision and management support (Gaede et al. 2006). Healthcare workers also found the biomedical orientation of the health system as a whole created barriers to person-centred care. Significantly, individuals who aspired and attempted to practice in a person-centred and holistic way, were seen to be especially vulnerable to burn-out. This was due to both systemic challenges and the overwhelming contextual issues of poverty, violence and inequity which lay at the root of people’s health problems.

The challenges of the public health system are acknowledged to impact negatively on healthcare workers’ relationships with communities (Gilson et al. 2005). The Patient Rights Charter and the Batho Pele principles for the civil service¹⁴ (KwaZulu-Natal Department of Health 2001) convey a code of practice for healthcare workers’ interactions with healthcare seekers, however the stressed state of the South African health system and low staff morale continue to impede their implementation (Gilson & McIntyre 2007; Schneider et al. 2010). Experiences of being treated disrespectfully by healthcare workers have figured prominently in South African users’ reported reasons for delaying or avoiding seeking care (Harris et al. 2014; Hasumi & Jacobsen 2014), including people with disabilities (Neille & Penn 2015; Swartz et al. 2011).

2.3.5.2. *Closeness to communities*

PHC proposes moving the point of healthcare engagement as close as possible to where people live and work (World Health Organisation 1978; World Health Organisation 2008a). This may include

¹⁴ “Batho Pele” translates as “people first”, and was established as a code of practice for civil servants in all South African sectors in the early years of democracy. Principles include access to information, courtesy, and transparency.

community-level and home-based services, as well as clinics and health posts. This not only reduces financial and logistical barriers to healthcare access, but also positions healthcare workers in contact with people's life context. This supports capacity for person-centred care, as clinicians have background knowledge of the socio-economic, cultural and physical world in which health is generated (World Health Organisation 2008b; Gaede et al. 2006). Such embeddedness in context is of particular importance for rural communities in South Africa, where healthcare workers frequently do not share the cultural and socio-economic background of healthcare seekers, and may make false assumptions about people's values, opportunities and capabilities in relation to health (Wilson et al. 2009; Braathen et al. 2013). For people with disabilities, proximity of health services is especially valuable for both logistical access and appropriateness of services. Rehabilitation in particular is best offered in people's home and life context, where contextual barriers and enablers to participation can be observed and addressed (Sherry 2015).

In South Africa, the District Health System (DHS) is responsible for delivering services at community and clinic level. Increased investment in PHC in recent years has increased the number of PHC clinics, especially in rural areas, however inequities in coverage and utilisation remain. Some clinics lack the basic services (e.g. water and telephone) and human resources to provide adequate services, while for an estimated 15% of households in poor rural areas, the nearest clinic is still more than an hour away (Gaede & Versteeg 2011). Rehabilitation, where available, is largely sited at district hospital level and above. Although a number of projects have established the effectiveness of cross-disciplinary mid-level rehabilitation workers to deliver CBR at community level, this cadre has not been taken up by the Department of Health to date (Chappell & Johannsmeier 2009).

2.3.5.3. *Continuity of care*

Continuity of care refers to the integration and coordination of the services people need over time, in the context of a sustained relationship between healthcare seeker and services. Existing healthcare in South Africa is often fragmented, with poor communication between levels and types of care, weak referral systems and difficulties with medical information systems (Naledi et al. 2011). This results in wasted resources and missed opportunities for both the health system and healthcare seekers. Although people with disabilities are known to have complex needs requiring multiple interventions and types of service over time (World Health Organisation 2011; Hwang et al. 2009), there is little evidence on the impact of service fragmentation on this population, particularly in a low-income context.

Continuity of care is supported by the ongoing responsibility of a healthcare team for the health of a given population. This is contrasted with a service approach that sees patients only in the context of discrete healthcare-seeking episodes, which may encourage fragmentation. PHC proposes that a localised healthcare team is allocated responsibility for the health of their geographic coverage area, whether individuals seek healthcare or not. This motivates more proactive interventions for prevention and health promotion, as well as action on local social determinants of health (World Health Organisation 2008a). PHCR in South Africa adopts this strategy in principle as the basis for Ward-based Outreach Teams (WBOT's), modelled on the success of PHC teams in Brazil's national health system (Mayosi et al. 2012). WBOT's comprise of both trained nursing staff and community health workers (CHW's) recruited locally. While aspects of this strategy are being rolled out nationally, implementation is uneven and has been plagued by insufficient resource allocation and disputes over the employment and working conditions of CHW's (Malan 2014; Lehmann & Gilson 2013). Le Roux and Couper (2015) point out the critical role of district hospitals and the professional teams attached to them in supporting WBOT's and other clinic staff in their work. The lack of coordination between

the PHC level (currently defined by policy as community and clinic level services) and district hospitals, is particularly problematic in rural areas (Gaede et al. 2006; LeRoux & Couper 2015).

WBOT's offer an ideal opportunity for bringing rehabilitation services, including mental health, closer to communities (Chetty 2015; Sherry 2015). Task shifting and sharing strategies involving mid-level workers have been shown to be effective and efficient ways of increasing coverage of these services (Spedding et al. 2015; Chetty 2015), although international evidence on mid-level workers conducting CBR remains limited (Mannan et al. 2012). Unfortunately to date, no provisions for disability-specific care and support have been made in WBOT development to date.

2.3.5.4. *A regular trusted point of entry*

There is substantial support in the PHC literature for a sustained relationship with a single healthcare worker over time, as a regular point of access to the system (World Health Organisation 2008b; Epperly et al. 2015). This is termed longitudinality, and evidence suggests that it produces greater satisfaction with healthcare, more timeous healthcare seeking, and more efficient and effective use of services (Lee et al. 2013; Ferrer et al. 2014). A natural fit is evident between longitudinality and person-centred care. A relationship between a healthcare worker and family that endures and develops over time, makes possible a rich understanding of healthcare seekers' health histories and personal lives. When a healthcare need arises, it can be addressed within this context. This is illustrated vividly in the account of Congregational Health Networks by Gunderson and Cochrane (2012). In their study of relational networks intentionally developed between religious communities and health services, these authors describe how a basis of mutual knowledge and trust greatly improves the efficiency and effectiveness of healthcare seeking among people with sickle cell disease.

The public healthcare service in South Africa makes no provision for healthcare seekers' preference to be seen by a particular healthcare worker, although consistent care by a specific person may happen by default at clinic level. High staff turnover in many facilities is a further impediment to the development of consistent relationships between healthcare workers and people with disabilities.

2.3.5.5. *Community engagement*

The Declaration of Alma-Ata expanded the roles of communities in health systems, by claiming for them a central place in the planning, governance, resourcing and delivery of services. PHC "requires and promotes maximum community and individual self-reliance and participation in the planning, organising, operation and control of PHC, making fullest use of local, national and other available resources, and to this end develops through appropriate education the ability of communities to participate." (Section VII, no 5, p 2, World Health Organisation, 1978). Paralleling the growth in participatory development strategies in other sectors, community engagement in health has since received substantial attention (Loewenson & Tibazarwa 2013; Flores 2011; Rifkin 2014).

Community engagement covers a wide variety of activities and approaches, including formal mechanisms within services, social mobilisation for health rights, and social accountability activities facilitated by a range of civil society actors (Cleary et al. 2013; Molyneux et al. 2012). In South Africa, legislation provides for health facility boards at all government health centres (Padarath & Friedman 2008). These committees must include representatives from both the local community and the healthcare staff, and meet regularly to discuss issues relating to health service delivery and governance. Unfortunately, although these bodies exist on paper in a large number of communities, their functioning varies widely. Lack of formal guidance as to their roles and scope, lack of training for committee members, absence of financial resources to support participation and local politics have all been cited as barriers to effective functioning (Padarath & Friedman 2008).

A major weakness in representative forms of engagement such as clinic committees is the difficulty of genuine representation of diverse members of any community (Cornwall & Coelho 2007). The concept of 'the community' has been widely questioned, and the election of representatives is often vulnerable to capture by local elites (Gaventa & Barrett 2010). People with disabilities who experience social exclusion are unlikely to have the opportunity to participate, not least because the spaces for participation may prove inaccessible (physically and attitudinally), especially in rural areas. Further, people with disabilities are a diverse group with differing needs, which a single representative may struggle to represent (World Health Organisation 2011). Finally, where people with disabilities have been excluded from education and other civic activities, they may lack the knowledge, skills and confidence to engage health services as citizens (World Health Organisation 2010).

A critical issue raised by practitioners in the field of community engagement since its inception is the real power afforded communities to influence health system agendas, and to make substantive decisions about planning, resources allocation and governance (Cornwall & Coelho 2007; Molyneux et al. 2012). In some instances, community engagement has taken tokenistic or even manipulative forms, with state or political actors using supposedly democratic processes to legitimise their own programmes (Gaventa & Barrett 2010). Formal mechanisms such as clinic committees have been described as 'invited' spaces for engagement, with the implication that community members engage on ground 'owned' by the health system, and governed by its rules. Asymmetrical power relations are likely to exist in such spaces, and unless measures are applied to alter these, citizens will have limited voice or leverage (Flores 2011). Alternative spaces may be 'claimed' or 'invented' by community actors as alternatives, and the literature on direct action and social movements describes a number of examples in South Africa, notably the Treatment Action Campaign (TAC)¹⁵, and landless peoples' movements (Campbell et al. 2010; Friedman & Mottiar 2005; Gibson 2011; Sinwell 2010). The disability movement in South Africa, led mainly by Disabled People South Africa (DPSA), is a powerful example of this kind of mobilisation among people with disabilities (Howell et al. 2006).

Social movements are based on the power of the collective, a type of social power foregrounded in other writings on community engagement (Miller et al. 2005; Loewenson & Tibazarwa 2013; Wallerstein 2006). What is less often discussed by proponents of social movements for health, is the necessary base of social cohesion and solidarity, as well as organising capacity, required to mobilise people in this way. Communities who lack this basis, or people within communities who are marginalised by existing social relations, will not have access to this power. A marked difference has been observed in the social mobilisation capacities of rural compared to urban populations, as well as in the kinds of power relationships existing between citizens and local government (Kenny et al. 2014; Lyons et al. 2002; Mansuri & Vijayendra 2013). This may be due to the logistical challenges of organising, levels of poverty resulting in lack of time or finances to engage in non-livelihood activities, and exclusion from mainstream society that concentrates in urban areas. Some rural communities, such as at the study site, may also have less access to the information and education required for engagement (Mansuri & Vijayendra 2013).

Much recent work has shifted focus from invited spaces such as clinic committees, to claimed and invented spaces, under the concept of social accountability (Flores 2011). Social accountability, loosely, describes interactions between state actors and citizens in which the former are held accountable by the latter, for the realisation of their right to the highest attainable standard of health, as detailed in legislation, policy and other undertakings. It is contrasted with state-centred

¹⁵ The Treatment Action Campaign is a broad-based civil society movement, which lobbied the South African government (successfully) for access to HAART from the late 1990's. They continue to campaign on healthcare issues at national and local level.

accountability, which involves the internal structures and processes by which state organisations regulate themselves (Flores 2011; World Bank 2004). Social accountability has gained prominence with the recognition that state-centred accountability frequently fails to achieve its purpose (Loewenson & Tibazarwa 2013).

Although definitions vary, forms of social accountability include monitoring activities such as citizen report cards, the use of formal participation mechanisms such as complaints procedures, and advocacy on specific issues (Loewenson & Tibazarwa 2013). Flores and colleagues, working in impoverished municipalities in post-conflict Guatemala, describe a programme building community capacity to monitor state-run clinic services and hold healthcare workers to account for healthcare quality (Flores et al. 2009; Flores n.d.). In the absence of functioning 'invited spaces' for community engagement in the health system, citizen groups were able to develop relationships of accountability with officials, and slowly rebuild trust between citizens and state.

While descriptions of tools and strategies abound, serious cautions have been sounded in recent years about the implementation of 'recipes' developed in one situation, in others, without careful attention to context. O'Meally (2013) reviews the available evidence on social accountability mechanisms, and argues that local social, political and other dynamics may be the ultimate determinants of the effectiveness of social accountability. These include factors within both state and civil society, as well as in the relations between the two, and echo to some extent the preconditions for effective community engagement with the state, outlined by other authors (Kenny et al. 2014; Piper & Deacon 2009; Flores et al. 2009; Flores 2011). In addition to the constitutional and legislative structures that establish rights, there is a need for transparency or answerability of the state, and leverage to enforce change where necessary (Gaventa & Barrett 2010). Where communities engage with frontline workers, it is critical that these staff have the power to effect change in the system (Flores 2011; Cleary et al. 2013).

Social accountability, in principle, is part of the practice of citizenship by all members of society in a democratic state, but in reality is usually least possible for the poor and marginalised, including people with disabilities and rural communities. Unfortunately, it is these groups who most often experience the service and governance failures that make social accountability activities necessary (World Bank 2004; Narayan, Chambers, et al. 2000). Through these and other mechanisms, community engagement activities may actually reinforce existing social marginalisation, rather than overcome it (Burger 2006; Gaventa & Barrett 2010; Mansuri & Vijayendra 2013).

What the above discussion has attempted to show are the limitations in existing strategies for, and knowledge about, community engagement in healthcare for people with disabilities. While South Africa has entrenched democratic processes and the right to health and to civic participation in its legislation, current socio-economic and political realities seem to prevent their enactment for our study population. The literature on social accountability has opened up possibilities for new forms of rights-based engagement, but is increasingly revealing their dependence on political and governance structures over which communities have no influence. The structural violence experienced by poor people with disabilities living in rural areas also excludes them from participating in specific ways, including capacity development for citizenship, and social and physical access to participatory opportunities. Where existing models of community engagement are thus constrained, there is a need to explore alternative practices of citizenship. This study therefore broadens the notion of engagement to include all the interactions between rural people with disabilities and PHC workers, and seeks out the ways in which these spaces are currently used to leverage healthcare needs.

2.3.6. Summary

This section has situated the study in the field of HPSR, and framed it within PHC, with reference to emerging notions of people-centredness in health systems. Health systems are understood to be inherently human and relational in nature, and to constitute part of the fabric of society. Core features of PHC systems were described, with reference to existing evidence on the South African health system. Little research is available on the engagement between rural people with disabilities and PHC workers, although the available evidence suggests this population to be systematically disadvantaged in both access to needed healthcare and opportunities to voice needs and hold health services accountable.

A strong emerging theme in the literature is the significance of social, economic, political, cultural and human factors operating at personal and household level, in shaping how all of these processes operate. The study of this micro level calls for richly contextualised qualitative case study methodologies, and a theoretical lens that captures these dynamics. The case has already been made for the capability approach as one such lens. We turn now to examine the concept of occupation, as a complementary construct in understanding the unfolding engagement of rural people with disabilities with health services.

2.4. Occupation

The study of occupation has a long association with the field of health, through its origins in the profession of occupational therapy. More recently, occupational science has emerged as a distinct field, encompassing the study of human occupation from a wide range of disciplinary angles and across diverse contexts (Yerxa 1993; Clark et al. 1991; Frank 2012). Researchers in this field, many of whom come from an occupational therapy background, have continued to concern themselves with questions of health, development and human flourishing, and have embraced human rights and social justice as core considerations (Townsend 2012).

Occupation in general terms refers to all of the things that people need and want to do in their daily lives, and not simply engagement in work, as per the common use of the term. Preparing a meal, taking part in a political protest, caring for a sick relative and herding the family cattle, are all occupations, with layered social, personal, and cultural meanings and requirements, which vary according to individuals, environment and situation. Occupation is a complex construct, including multiple dimensions (Fogelberg & Frauwirth 2010; Aldrich 2008), and is considered to be fundamental to human nature and existence (Wilcock 2006).

While a detailed examination of existing occupational science theory and research is beyond the scope of this review, the following section will outline selected aspects with application to this study.

2.4.1. Occupation and environment

Disability has been defined as the experience arising from the interaction of a person with a health condition, personal factors, and the environment, with the 'fit' between these determining the level of function and participation that is possible (World Health Organisation 2011; World Health Organisation 2001). A similar concept has been proposed to understand how people access health services, with access to healthcare being conceptualised as 'degree of fit' between the properties of the system and of healthcare seekers (Saurman 2016; McIntyre et al. 2009; Penchansky & Thomas 1981). In turn, health systems have been argued to be embedded within the societies they serve, with the broader context, in its many dimensions, powerfully influencing how health services function and

interact with communities (Frenk 2010). The construct of occupation as arising in, and even constituting, the interface between human beings and their environment (Dickie et al. 2006), offers a potentially useful means to examine both disability and aspects of health system functioning, in a multidimensional manner.

The relation between person and environment as fundamental to occupation is almost axiomatic. Environment, according to the ICF, is taken to include physical, social, institutional, cultural and personal factors (World Health Organisation 2001). These factors together create both opportunities and requirements for engaging in various occupations, as well as shaping the specific ways in which things are done (Creek 2010; Nelson 1988). Recent authors have questioned thinking within occupational science that assumes a dichotomy of person and environment (Cutchin & Dickie 2012a; Dickie et al. 2006). They argue for a transactional view of occupation based in the theories of John Dewey, which perceives people and their environment as a co-constituting, functionally coordinating whole, rather than individuals as autonomous 'doers' operating within an environment outside themselves (Cutchin & Dickie 2012a; Aldrich 2008). What is significant for this study is the recognition of how 'environment' also resides and expresses itself within the person and her occupational engagement, particularly where historical, socio-political and cultural dimensions are considered (Galvaan 2015; Townsend 2012), and how people themselves both shape and constitute the environment, including for other people's engagement (Ramugondo & Kronenberg 2015).

Another reason to move beyond the individualistic stance of person-environment dualism, is the conceptual fit with African cosmology. The interconnected and co-constituting nature of human beings is expressed in the concept of Ubuntu (Cornell & van Marle 2005) and this was understood to frame all of the doings and choices of our participants. Ramugondo and Kronenberg (2015) propose that human relations form a primary motivator for individual and collective occupation, and that occupations themselves are "a vehicle to building and sustaining relationships that work" (p 12). Following Cornell and van Marle (2005), they argue against perceiving the individual and the collective as dichotomous, seeing the two as existing through constant dynamic and reciprocal interaction. In this way, individual capability and responsibility are kept in balance with community belonging and obligations, rather than subsumed under the collective existence.

For the purposes of the study, it remains useful to distinguish between individuals and the setting in which they operate, including the community. We will however differentiate between environment, context and situation. The term 'situation' was used by Dewey to refer to "the multi-faceted, spatially and temporally dependent events that provide the basis of active experience" (Cutchin 2004, p 305). A person's situation includes the specifics of a time, place and problem arising within the unfolding narrative of his life, which Rosenberg and Johansson (2013) argue to be the appropriate unit of analysis for transactional research in occupational science. In our study, the situations of interest were marked by the emergence of a health need for a person with a disability, which gave rise to healthcare seeking (or a choice not to do so). Each such situation was unique, embedded within the life and illness stories of the individual and the household, and coinciding with other events and conditions, for example other demands on family resources, the roles and responsibilities of the person with a disability at the time of becoming ill, and previous experiences of healthcare seeking. The attention implied in the transactional view to the specific, contingent and dynamic details of people's engagement, fits well with the micro lens adopted for this study.

Context will be the preferred term to denote the dynamic interplay of social, physical, temporal, historical, cultural, institutional and spiritual factors that make up our participants' life-space. Creek (2010) defines context not simply as an array of factors, but rather "the relationships between [these factors] that influence the meaning of a task, activity or occupation for the performer" (p 25). The

specific reference to the salience of certain aspects, within an almost infinite array of environmental attributes, is helpful. The term environment will be used non-specifically, for example to refer to the physical terrain in the study site, or the sensory and social features of the clinic setting. Situation may thus be seen as nested within context, and context in turn, within environment.

2.4.2. The organisation of occupation

The construct of occupation proposes in essence that human behaviour is patterned and organised. Many different concepts have arisen to describe and explain how and why people use their time and exert their energies in particular ways, and a variety of paradigms have been employed to conceptualise occupation. These have included structural, transactional, existential and phenomenological perspectives (Cutchin 2004; Kuo 2011; Wilcock 1999; Dickie et al. 2006; Pierce 2001). For example, Wilcock (1999), adopting an existential position, defines occupation as a synthesis of doing, being and becoming, while Pierce (2001), from the phenomenological viewpoint, considers occupation an individual, unique and unrepeatable experience. Cutchin (2004), argues against such an individualised view of occupation, and proposes a Deweyan transactional conceptualisation encompassing person and environment as a functionally coordinating whole (Dickie et al. 2006; Cutchin & Dickie 2012b; Cutchin & Dickie 2012a). While transactional constructs have been incorporated into the study, a structural-functional approach to defining and describing occupation was adopted. One reason for this was the focus on health as the goal and outcome of occupation inherent in a health systems approach. Another reason was the difficulty of interpreting participants' existential experience of engaging with the health system, in a cross-cultural research context.

A core proposition within occupational science is that occupations, by definition, possess both meaning and purpose. Purpose tends to relate to the more practical ends of doing something (in our case, health), while meaning has to do with the perceived significance of doing, in relation to existential dimensions such as personal values and cultural frameworks (Kuo 2011; Ikiugu 2005). In practice, the two are closely intertwined, and together may describe both the motivation for engagement, and the experience of doing so. One well-known definition of occupation describes it as "chunks of culturally and personally meaningful activity that can be named in the lexicon of the culture" (Clark et al., 1991, p 30). The focus on purpose and meaning associated with human 'doing' establishes occupation as construct, at the level of organising what motivates and sustains human 'being'. Activities and tasks are seen as embedded within this construct of occupation, as the stuff of which occupations are comprised.

The complex structural composition of occupation is elaborated by Harvey and Pentland (2010), who propose that occupation as a whole is made up of roles, tasks and activities. Roles are aspects of personal identity and functioning that situate one socially and existentially, for example the role of being a mother, a worker or a citizen. They endure over time, and may be enacted in different ways in different times and places. This enacting of roles is made up of tasks, which are "chunks of activity" with defined purpose in themselves, while activities are the steps making up the task. For example, the role of mother may require, when a child is ill, the task of taking her to the clinic, which will include the activities of walking there, waiting on the benches with the other patients, speaking with the nurse and carrying out the treatment as instructed at home. The specific definitions and distinctions of the levels are contested, but the principle that all occupation takes place within an organising framework of purpose and meaning, which is socially, culturally and personally situated, is taken as foundational.

Because these meaning frameworks differ from person to person, it is common for the same tasks and activities to be enacted with entirely different meanings, and towards different goals (Pierce 2001).

This is especially significant in the context of our study, and stands in contrast to public health understandings of ‘health-related behaviour’ (for example eating, exercise and sexual activity), as often divorced from their social, cultural and personal contexts (World Health Organisation 2008a). The construct of occupation offers a richer and more nuanced approach to understanding people’s actions or non-actions, with important implications for healthcare interactions, interventions and expectations.

2.4.3. Occupation, health and development

Occupation is a means by which people may pursue health (through their engagement with their environment to survive, develop and thrive), and the process of engaging in itself impacts on people physically, mentally, socially and emotionally, either positively or negatively, depending on the unique situation and manner in which one engages, and the fit between person, context and occupation (Christiansen et al. 2015). Obvious examples are the physical and mental illnesses and impairments sustained through dangerous working conditions, contrasted with the personal, social and spiritual well-being resulting from engaging in community celebrations and rituals. Wilcock (2006; 2007) claims an almost inseparable relationship between occupation and health, and traces evidence for this across diverse fields and eras of research, including current public health work that focuses on health promotion and disease prevention.

The difficulties of defining health have been addressed in the first section of this chapter, and it was proposed that health be considered within the capabilities perspective. Clear linkages exist between the constructs of occupation and of capabilities, with both focusing on what people are able to be and to do, that they value and have reason to value (Hammell 2015), as well as on the personal and environmental factors that enable or obstruct them (Hocking 2013). Occupation can be seen both as the means by which capabilities are pursued (for example, someone who studies at university in order to have the capability to choose valued work, or to provide for a family), and as the ends, the capabilities themselves (for example, the capability to engage in education). Whiteford and Pereira (2012) suggest that occupational science and the capabilities approach share concerns with not only what people are able to be and to do, but also their opportunities to develop those capabilities.

In this study, the capabilities approach and occupation are seen as complementary. The former provides the value framework within which people with disabilities’ engagement with health systems can be interpreted. Occupation, as defined above, provides the lens through which the processes of engagement can be understood as embedded in context, enacted in time and space, and embodied in the experience of disability.

2.4.4. Occupation, human rights and social justice

Occupational science and the capabilities approach share a central interest in human agency, and the opportunities afforded by the context to engage in valued occupations. The problem of inequalities of opportunity has been argued by Hammell and Iwama (2012) to be an issue of ‘occupational rights’. This both overlaps with and extends the concept of human rights, going beyond the ends (for example the right to be healthy, safe, or educated), to include the means or processes of achieving these as rights in themselves. A historical focus on the participation of people with disabilities, has resulted in a great deal of occupational science work focusing on the barriers and facilitators to occupational engagement in society (Whiteford & Hocking 2012; Townsend 2012). More recently, this social justice theme has been expanded to encompass the experiences of other groups, including refugees,

prisoners, people living in conflict zones, and youth at risk (Kronenberg et al. 2011; Kronenberg et al. 2005). Occupation is proposed as the mechanism by which people have the opportunity to thrive, develop and realise aspirations (Hocking & Whiteford 2012), and the concept of occupational justice has emerged to describe the existence of conditions in which this is possible for all, without discrimination (Nilsson & Townsend 2010; Townsend & Whiteford 2005). A critical perspective is being applied to understand how structural inequities and social, political and historical forces contrive to prevent this (Whiteford & Hocking 2012). A growing body of work by South African occupational therapists addresses these dynamics for different groups in this country, including people living with HIV/AIDS, youth at risk, and people with mental illness in impoverished communities (Duncan et al. 2011b; Watson & Swartz 2004; Galvaan 2015). Of particular relevance to this study is work on poverty, disability and occupation dynamics, both in peri-urban and rural areas (Duncan & Watson 2009; Duncan 2009).

The construct of citizenship has been considered in relation to participation and social inclusion, as enacted through people's daily occupations (European Network for Occupational Therapy Higher Education (ENOTHE) 2013). Few studies exist of the occupations of citizenship in impoverished contexts. This study proposes that by understanding how such occupations are shaped, constrained and adapted, it may be possible to design interventions that facilitate this engagement at the micro level, where rural people with disabilities engage with health services.

2.4.5. Cultural conceptions of occupation

It has been well acknowledged in recent years that the study of occupation, as also the profession of occupational therapy, is strongly rooted in a Western philosophical and knowledge tradition (Kantartzis & Molineux 2012; Watson 2006; Hammell 2009; Kinsella 2012). A core criticism, also applied to disability research, has been the bias towards individualism and the Western cultural value of independence, which stands in contrast to the relational and collective frameworks of many non-Western cultures (Kirby 2015; Iwama 2005). As yet, alternative thinking about occupation grounded in African ways of knowing, is in its early stages, although Ramugondo and Kronenberg (2015) open up important conceptual possibilities and direction for this work, as described above. Kinsella (2012) proposes that occupational scientists need to adopt pluralistic perspectives in the study of occupation, enabling reflexivity about the ways in which existing paradigms in the field shape the production of knowledge. Openness to questioning assumptions will allow other ways of understanding occupation, rooted in different cultural perspectives, to be explored. The cross-cultural context for this study offered challenges in moving beyond my own personally and professionally shaped thinking about occupation, but also opportunities to build alternative ideas based on Xhosa ways of being, doing and knowing.

2.4.6. Summary

This section has introduced the concept of occupation within the field of occupational science, including key features of its organisation and substance, and demonstrating conceptual and ideological links with the capabilities approach introduced earlier. The challenge has been identified to move beyond Western paradigms for occupation to explore the implications of African ways of being, doing and knowing. Concerns with social justice and social inclusion are highlighted in the literature. This study aims to contribute to empirical research on the enactment of citizenship through daily occupations, specifically by people marginalised by poverty and disability.

2.5. Conceptual framework

As outlined above, this study positions itself within the field of Health Policy and Systems Research, with a specific focus on the interface between the health service and the community it serves, underpinned by PHC principles.

The concept of the interface between communities and the health and development organisations who seek to serve them, has been developed in the work of Long on Actor Oriented Analysis (AOA) (2003). He offers the following key assumptions which underpin this study:

- People respond in very different ways to the same set of circumstances. Human agency interacts with the complex array of contextual factors to produce unpredictable outcomes to development interventions.
- Macro-level dynamics, including political, social, economic and historical issues, play out at the micro level where people engage with organisations.
- The interface between an organisation (such as the health system) and a community is made up of various interlocking spaces which feed into and influence each other.
- Different cultures collide in the interface, giving rise to conflict, negotiation and creative reinterpretation (Long 2003).

While Long's principles have informed some of the health policy analysis work described above, most existing research addresses only one or two aspects of a given healthcare interface (e.g. (Walker & Gilson 2004; Lehmann & Gilson 2013). No studies were found which applied the interface principles more broadly to health systems, to examine multiple spaces and the interconnections between them. Such work holds considerable potential in the study of health systems, and fits logically with the understanding of their embeddedness in context.

To investigate the interface between people with disabilities and primary health care services, we began by mapping the available participatory spaces making up the interface. Participatory spaces were defined as moments of opportunity where people with disabilities were able to engage PHC workers to their own valued ends, and vice versa. Such spaces included formal opportunities, such as a visit to the clinic, as well as informal ones, such as meeting a healthcare worker by chance in the location. Descriptions of the participatory spaces were built up through the emerging narratives of the eleven participant households, which allowed the PHC interface to be contextualised within the life spaces of rural people with disabilities.

An occupational lens was applied in the co-production of participant narratives, i.e. events were understood in terms of what people actually did in space and time to seek healthcare, and how this affected the other things they needed and wanted to do. The capabilities approach was used as a value framework, placing emphasis on people's agency in pursuing things they valued being and doing. Table 1 summarises the core assumptions of the study.

Table 1: Core assumptions of the study

Assumptions	Source
Health systems are primarily human and relational, complex and contextual, and are embedded in the fabric of society	People-centred health systems
The valued ends of development are capabilities, i.e. the things that people themselves want to be and to do given the available opportunities	Capabilities approach

and resources. Healthcare is not an end in itself, but a means to realising capabilities.	
Occupation is the means by which people pursue and exercise capabilities. What people actually do in a given situation is shaped by context, personal factors, culture, values, social roles and relationships and practical considerations. People's health is created and maintained (or not) through their occupational engagement.	Occupational science
People consistently exercise agency, pursuing choices which align with what they value being and doing in context.	Actor oriented analysis Capabilities approach
Health is not only biomedical, but defined by people themselves according to the things they value being and doing (i.e. capabilities). In an African context, it has a strong relational dimension. Health and daily occupation shape one another in an ongoing dynamic.	Capabilities approach African philosophy
Healthcare is not 'delivered', but co-constructed as people engage with healthcare workers in the PHC interface.	Primary health care Person-centred care
Disability is not a fixed characteristic of an individual, but an experience arising from the interaction of a person with a health condition in her environment (which includes the health system itself). Disability constitutes a 'conversion factor' in access to healthcare.	ICF Capabilities approach

2.6. Summary of chapter 2

This chapter has explained the health systems significance of how health and disability are conceptualised, and has proposed a capabilities definition for both. This positions the health system within the broader development context, aligning it with human rights and poverty alleviation, and establishing disability as a critical issue for health system design and functioning. PHC philosophy has been compared with both policy and realities in the South African health system, in the context of current efforts to achieve universal coverage. Existing approaches to community engagement are failing to bring the voices of rural people with disabilities to bear on health service organisation and delivery. The literature suggests that for this population, neither 'invited spaces' nor social mobilisation are likely to provide the solution, without major changes in the structural conditions of poverty and the existing imbalances in social and political power. The rationale for this study holds that alternative practices of citizenship may be identified through in-depth study of the micro-level interactions between people with disabilities and PHC workers. Little research has been done to date which explores this interface in the context of rural poverty and underdevelopment.

Chapter 3: Methodology

3.1. Introduction

This study addressed the need for micro-level research into the engagement between rural people with disabilities and PHC services. The methodology needed to provide space for the perspectives and experiences of people with disabilities, with detailed understandings of the contextualised occupations through which they pursued health needs. Cultural sensitivity and openness to challenging researcher assumptions about the world were imperative. These concerns shaped the development of an interpretive qualitative case study approach, using ethnographic methods to co-produce narratives of PHC engagement with eleven people with disabilities from Kwabisi location.

3.2. Theoretical approach

The key methodological elements of the study are summarised in Table 2, and elaborated upon below.

Table 2: Summary of methodological elements

Element	Stance
Field of inquiry	Health Systems and Policy Research (HPSR)
Paradigm	Qualitative
Theoretical orientation	Interpretivism
Conceptual framework	Capability Approach with Occupational Science
Methodology	Embedded case study
Methods	Ethnographic: narrative interview, participant observation, key informant interview, document review

3.2.1. Field of Inquiry

This study situates itself within the field of Health Policy and Systems Research (HPSR), a relatively new field, but receiving growing attention internationally. In a shift from previous health research focus on specific interventions, with little attention to how these are delivered to communities in different settings, HPSR seeks to understand how efficient, integrated, equitable and sustainable systems can be built, to offer responsive healthcare to populations (World Health Organization 2012). Awareness of the need to strengthen health systems has grown as the mismatch between available technologies and actual population health outcomes becomes increasingly evident, particularly in low and middle income countries (World Health Organisation 2007; Sundewall et al. 2011). The current concerns with achieving equity through universal health coverage, PHC and PCHS have already been discussed.

HPSR spans a variety of approaches and disciplines, with a strong emerging role for the social sciences, alongside the more established health research contributions of the biomedical, clinical and

quantitative sciences (Gilson et al. 2011). HPSR is characterised by close engagement with the practical challenges faced by health policy and decision-makers, clinicians and other stakeholders, and a trans-disciplinary approach to problem-solving (World Health Organization 2012; Gilson 2012).

3.2.2. Qualitative paradigm

Qualitative research aims to understand the social world through exploring the experiences and perspectives of social actors. Qualitative research in itself is an extremely broad field, and therefore it is necessary to articulate precisely what approach, both philosophical and methodological, was adopted (Savin-Baden & Major 2013). While a quantitative outlook tends to predominate among health researchers, clinicians and policy makers, there is an urgent need for insight into issues that cannot readily be quantified, for example the nature of relationships and social dynamics within the health system (Gilson et al., 2011). Qualitative research is often used to explore a topic about which little is known, and is invaluable for challenging the assumptions which underpin both clinical practice and quantitative research in health. This research aimed to understand underlying systems of meaning, behaviour, social dynamics and social structures, in a setting about which little is known, and therefore a qualitative approach was most appropriate.

3.2.3. Interpretivist orientation

The importance of acknowledging and examining the philosophical beliefs underpinning any research endeavour is widely acknowledged. For this study, I have identified my core position as interpretivism. Following Savin-Baden and Major (2013), I will set out in more detail what I mean by this term, and its implications for the research methodology.

Interpretivism falls within the philosophical tradition which views reality as existing in the perceptions and experiences of human beings, rather than as something independently constituted from the 'knower' (Guba & Lincoln 2008). The researcher is seen to participate in constructing knowledge, both in interactions with participants, and through her own meaning-making throughout (hence the use of the term 'data generation', in preference to 'data collection'). Findings can never be claimed as objective fact, but rather as interpretation and representation. Constructed rigorously and transparently, such accounts are seen to hold truths that are valuable without needing to claim universality, or be 'proven' by independent means (Savin-Baden and Major, 2013).

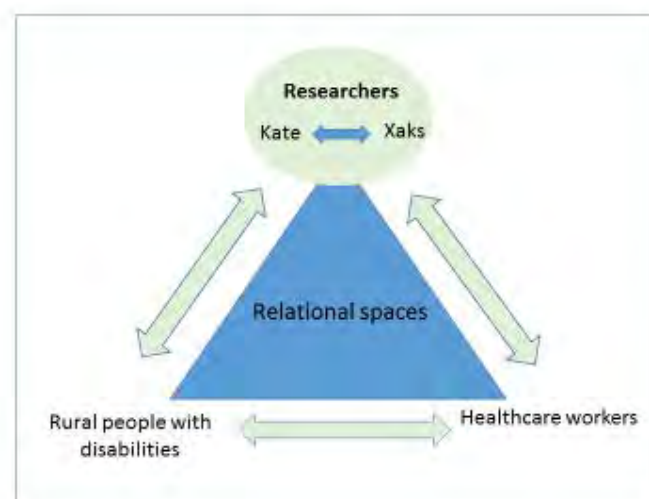
The interpretivist ontological position fits naturally with a research focus on human experience, which acknowledges the multiple co-existing ways of interpreting any given situation, and considers the variety of experience and perspectives worth studying. The cross-cultural research context made sensitivity to these differences especially significant, and during the course of the study, I often needed to question how my own frameworks for reality differed from those of my Xhosa participants. In the field of occupational science, Kinsella (2012) argues that allowing for plurality of perspectives in occupational science enriches knowledge. In this study, the disjunctures and tensions between our differing perspectives were themselves the essence of the participatory spaces we wanted to study.

The interpretivist standpoint holds that it is impossible ever to fully know what another person knows, so that research is always a process of getting as close as possible, but never being able to claim full insider knowledge (Cousin, 2010). Questions of insider/outsider status are central to ethnographic and critical research, although such positioning is understood to be relative to situation. During the course of the research I moved slightly down the continuum from outsider to insider, but relied greatly on Xaks as a relative insider for my growing insight.

Knowledge was seen as not only existing in the experience of the individual, but also being constructed through social interactions and relationships, including throughout the research process. The Xhosa way of being in the world emerged as essentially collaborative and relational, with people's essence existing in their relationships to one another and to the social whole (Cornell & van Marle 2005). This shifted the research focus from experiences conceived as belonging to the individual, to the ways in which experiences were relationally produced and defined. Openness to alternative worldviews is inherent in interpretivism (Kinsella 2012) and a reflexive approach made possible this kind of paradigm shift within the research process. At the same time, the research aimed to interpret people's experiences in the light of health systems concerns, which required that their stories be studied within the social, political, economic, historical and physical context. Rather than assuming an entirely relativist approach to value, we needed to ask questions about the purpose and ends of the health system within society, raising questions about public good and the nature of health. Issues of human rights and equity underpinned the research question, and the overall intention was to produce applied knowledge that would further these causes.

It soon became clear that each research encounter contained a social dimension which reflected tellingly on relationships within the healthcare interface. The interviews themselves could be interpreted as socially constructed, with our positionality as researchers (particularly mine as a marked "outsider"), playing a significant role in how participants chose to tell their stories, and the data itself emerging as a process of co-construction (Flick 2009). We also realised that our interactions with healthcare workers and officials could reflect qualities of the system which would carry across to the interface with our participants. It was decided to consider all of these social dynamics as an additional source of data. The triangle in Figure 4Error! Reference source not found. depicts the interlinking relational spaces making up the research.

Figure 4: Relational spaces in the research



Understanding and accounting for researcher positionality is a core component of the interpretivist stance. In contrast to positivism, which holds it possible for a researcher to be an objective observer without influence on the subject of research, this epistemological position emphasises how the person

of the researcher influences both the knowledge generated, and how it is interpreted (Cousin, 2010). In this study, the significant differences in cultural and socio-economic background between myself and the participants made this a central consideration. Critically, the research had to take account of the post-colonial and post-Apartheid context, and the ways in which issues of race, class, gender, geography, politics and history played out in the field, particularly in the research relationships. Smith (1999) cautions against the dangers of imposing alien frameworks and interpretations on indigenous people's knowledge and experience. The growing movement for critical indigenous methodologies highlights the political nature of knowledge generation, and the ways in which the Western approach to research has contributed to oppression of marginalised groups (Denzin & Lincoln 2008). It draws attention to the performative dimension of research, and calls for processes that are collaborative and emancipatory, with power over questions, methods and findings being held by indigenous participants themselves. There is a call for indigenous values to replace Western ideas in informing research ethics and engagement, and for indigenous knowledge systems to be interpreted on their own terms, without the imposition of outsider theories and world views (Denzin & Lincoln 2008; Owusu-Ansah & Mji 2013). Similar concerns are raised by disability scholars, in the light of historical power relations between non-disabled researchers and people with disabilities (McKenzie et al. 2014).

Participatory action research (PAR) has for some time been the preferred methodology where research intends to give voice to vulnerable and marginalised people (Bozalek 2011). PAR aims at sharing control over the research process with participants, attempting to reduce power differentials between stakeholders and creating opportunities for participants to benefit directly by steering the process towards their own interests and needs (Guba and Lincoln, 2008). The previous research project (People informing Policy: Power and Progress [PPP]) adopted a participatory approach, and during the time I spent in the area thereafter, I was able to observe how the community's learning through the research process was beginning to bring about positive change. However, the project had also revealed many challenges in engaging people with disabilities in this setting, including logistical and resource demands, as well as the deep cultural divides between the outsider researchers and the participants. In devising the current study, I knew that I lacked both the resources and the skills to carry out such a process alone, even with the invaluable help of Xaks. It was also clear that local residents were experiencing a measure of 'research fatigue', and might not wish to engage intensively with us.

I realised my own urgent need for a better understanding of the lifeworld of rural Xhosa people with disabilities, if I was to learn about how health systems could better serve them. I therefore claimed the research question and process explicitly as my own, but sought a sensitive and reflexive approach which aimed to balance maximum learning with minimum imposition on participants.

3.2.4. Case study design

Case study design allows for in-depth study of phenomena within their context (Yin, 2009), and is therefore particularly valuable in the study of how health systems interact with the greater social realities of which they are a part (Gilson, 2012). The units of analysis in this study were both the eleven participant households whose stories we collected, and the interface between villagers and local health services as a whole. This is described in the literature as an embedded case study (Yin, 2009). Each participant case helped to build our understanding of the interface, and the sample of eleven allowed for a degree of cross-case comparison. It was thus possible to identify themes and patterns in

health service engagement, test these through negative case analysis, and create a nuanced description of the whole. Each case was built up over time, using multiple data sources.

For the study to be of use beyond its own immediate sphere, the question of generalisability needed to be addressed. The very small scale of the case made statistical generalisation obviously impossible. However theoretical, or analytical generalisability (Yin, 2009), is the capacity of a small number of cases to generate theoretical insights that can be applied usefully elsewhere. Concerns for analytical generalisability were addressed through the measures for rigor in data generation and analysis described below.

3.2.5. Ethnographic methods

Ethnography seeks to describe and understand, from an emic perspective, the culture or lifeworld of a particular group of people (Spradley, 1980). From its origins in anthropology, it has become widely used in other fields, with various methodological adjustments over time. The development of medical anthropology has led to ethnographic methods being applied to healthcare settings such as hospitals, as well as to the health-related practices and beliefs of different social groups (Helman 1994). HPSR and the related fields upon which it draws, regularly use ethnographic approaches to study health systems in context, although the lengthy immersive process of traditional ethnography is seldom possible within the constraints of such research (Kielmann 2012).

In this study, the focus was the interface between two distinct worlds, i.e. that of a rural village of amaBhaca people, and of a state healthcare service, shaped by national and provincial policies, local socio-political dynamics, and a 'culture' of civil servant healthcare workers. Both worlds needed to be understood on their own terms, before the interactions between them could be interpreted. Because the research aimed to foreground the perspective of villagers, as seldom-heard voices in the health service space, the ethnographic focus was on this community and their world. I chose to spend time living in Kwabisi while conducting the case studies, so as to better understand the background against which they took place. From this social, physical and geographical positioning, we then (re)entered the health service space through the narratives of the eleven participant households, both as they were told to us, and as they continued to unfold during the data generation period. The ethnographic methods employed in the study included immersion in context, participant observation, narrative interviewing, key informant interviews and document review.

3.2.6. Narrative approach

I chose to structure the eleven cases around their personal narratives, as these were told to us and also unfolded during the research period. A narrative approach fits well with the interpretivist stance, and stories are considered a naturally-occurring form of human and social meaning-making (Greenhalgh, 2006). Narrative interviewing provided both structure and space for participants to choose what they shared, and often led to hidden factors and unexpected associations being revealed. While many stories included elements covered in other research on healthcare access, for example transport barriers and costs, they also reflected how such factors interacted in different circumstances and led to different choices and outcomes. The temporal dimension of healthcare access could also be captured, for example the impact of successive healthcare failures on future interactions, and the narrative reasoning (Mattingly, 1998) that informed how households approached health issues.

Narrative inquiry has been considered a culturally sensitive and safe approach in cross-cultural settings and with vulnerable populations (Neille and Penn, 2015). I had previously found more direct and analytical questioning, as is commonly used by researchers in semi-structured interviews, to be

subtly resisted in this context. Inviting story-telling proved to be both simpler and more acceptable to participants, as well as allowing them substantial control over the process. The dialogic conception of narrative, as proposed by Bakhtin (1984, in Greenhalgh 2006), highlighted the social construction of the stories we encountered, and the need to interpret them from this perspective, rather than as direct representations of participants' own sense-making.

Narratives have also commonly been interpreted in the light of a shared cultural repertoire of references, themes and plot lines, upon which tellers may draw to make sense of events, and to convey these to others (Holley & Colyar 2010). Story-telling about health and illness has received particular attention from this perspective (Greenhalgh 2006; Aronson 2014). However, without sharing the cultural and linguistic background of our participants, I was not in a position to apply this kind of interpretation, and analysis needed to be extremely wary of assumptions which might be culturally biased. Krog, Mpolweni and Ratele (2009) present a powerful account of the dangers of interpreting stories out of their cultural, social and linguistic context, and of the complexities in seeking alternative methodologies for interpretation.

Woven into the stories of our participants was our own story as researchers. Some of our participants had also been part of the PDO and PPP studies, and the two primary researchers in those projects had played significant roles in their lives, assisting with access to services, writing referral letters and providing practical support of various kinds. One of the researchers had taught several women in the community to sew, sourcing machines, patterns and fabric for them, and helping initiate a valuable source of income as well as a valued occupation. During the current research project, Xaks and I had opportunities to continue these supportive relationships. Doing so greatly enriched the data, but also proved ethically, morally and personally significant.

3.3. Sampling

3.3.1. Case selection

Our arrival at Kwabisi as the study site has already been described in Chapter 1. The village showed characteristics typical of this region and of other homeland areas of South Africa, including limited services and infrastructure, dispersed settlements, a traditional authority structure, and a population experiencing multiple and serious socio-economic challenges. Du Toit and Neves (2007) describe the area as a typical 'rural poverty trap', where historical, political and socio-economic dynamics combine to perpetuate chronic poverty and prevent mobility out of this state. There is reason to believe that health issues and costs play a role in this cycle, and that disability itself serves to exclude people from development opportunities.

The case study area included the villages making up the Kwabisi location, as well as the state health services serving this population. These included a PHC clinic, staffed by a professional nurse manager and two to three enrolled nurses¹⁶, as well as a data capturer, general assistant and several community health workers, known in this area as *nomakhayas*. The clinic manager had worked in the clinic for over twenty years, and was well known in the community, although she was not a local resident. All of the nurses lived in staff quarters at the clinic during the week, and travelled home on the weekends, some living up to two hours' drive away. The clinic was open five days a week from 8 until 4. It provided basic and routine healthcare, including antenatal care, HIV/AIDS testing and counselling, dispensing of chronic medication including HAART and psychotropic drugs, and attending to minor ailments and

¹⁶ Non-professional level of qualification, also called staff nurses

injuries. Staff did not provide emergency care or perform deliveries, and ambulance services from town were scarce and extremely unreliable, a common source of complaint among our participants.

The district hospital in town included approximately 100 inpatient beds, and an outpatient service staffed by nurses and doctors. No doctors or therapists conducted outreach to the clinic during our time there, and participants could only see a doctor in town, either at the hospital, which entailed long waiting times, or at one of the private general practitioners operating in the area. The latter were cash practices paid for on an out-of-pocket basis, and although fees were many times that of an outpatient hospital visit (R150-R200 [US\$9-13] compared to R20¹⁷ [US\$1,30]), many people preferred to pay to see a 'special doctor' (despite receiving care which, according to the reports we heard, was often dubious).

Rehabilitation services at the hospital included an audiologist, occupational therapist, physiotherapist and two to three rehabilitation assistants (numbers varied during the research period). Assistive devices including basic wheelchairs, crutches and hearing aids were provided when available, but often subject to waiting times of months to years, due to significant backlogs.

At clinic level all healthcare was provided free of charge, and at hospital level people with disabilities were officially exempt from user fees, although this was not always implemented by administrative staff. Assistive devices were charged for on an income-related sliding scale, when available. Financial barriers to accessing care tended to be transport-related rather than due to user fees.

Very little public transport operated in the Kwabisi area, and some people needed to walk several kilometres to reach the clinic. Where this was not possible, a private vehicle needed to be hired from a neighbour, which could cost the same as public transport to town (R50 or US\$3,16). Transport to town was in the form of two to three small pick-up vehicles fitted with makeshift seats, which were invariably heavily laden and crowded. Wheelchair users were required to pay a second fare for their chairs, and drivers were known to bypass people with disabilities waiting for lifts. These vehicles (known as *gugqas* or *gurugurus*) tended to make one trip into town in the morning, and return in the late afternoon. Apart from a single government bus which departed in the early morning, no other public transport operated in the area. Neither of these options was accessible for people with physical disabilities. Transport outside these hours was only possible through private vehicle hire, which could be exorbitant, particularly if required at night or in an emergency. State ambulances operated from the town, but were few, poorly coordinated, and drivers were often unwilling to travel the poor roads and long distances to fetch rural patients.

3.3.2. Sampling criteria & method

Our primary participants (referred to hereafter as "the participants") were people with disabilities living in the Kwabisi area, and their households. Potential participants were identified from our previous research, by the local community health workers (*nomakhayas*), and sometimes by other participants themselves (snowball sampling) (DePoy & Gitlin 2011). Inclusion criteria were kept broad to capture variation in experience, and there were no exclusions for age or ability. Where the person with a disability was unable to engage in the research conversation, the primary caregiver and/or head of household was invited to speak on his/her behalf, including providing consent and telling the story. Given the close interdependence of household members in this setting, the inclusion of other household members in the data generation process was key, and arranged wherever possible.

¹⁷ In theory, user fees are waived for people with disabilities, although this is not uniformly implemented.

Sampling aimed at maximum variation in terms of age, gender, household composition, health issues, impairment and healthcare experience. Convenience did however play an important role, specifically the openness of the household to engage with us (DePoy & Gitlin 2011). While no household we approached refused to speak to us, certain people offered only superficial information, and did not respond to probes for more. Households who had been involved in the previous research proved generally more amenable to taking part, possibly because they were already familiar with the concept of research (not otherwise well understood in the area), and were also at ease with Xaks. The positive relationships formed by the previous UCT researchers with their participants were also highly significant in people's attitudes towards us. The background knowledge about these households held by Xaks was often useful, although the current research question was sufficiently different from previous studies for substantial new data to emerge.

3.3.3. Sample size and composition

Sample size was limited by time available in the field, which had to take account of travel and frequent challenges with arranging visits with households without regular access to telephone communication. Community entry also added greatly to the time demands of the project. The nature of engagement required to build up each case to the desired depth, made data generation time- and energy-intensive, resulting in a smaller number of cases than originally intended (15-20). However, the range of experiences and perspectives presented across the eleven cases was rich, with sufficient commonalities to form a coherent body of data, and sufficient variation to argue for reasonably broad representation within the overarching Kwabisi case.

The eleven households included in the sample are described in Table 3 (note that all names are pseudonyms).

Table 3: Participants

Name	Gender	Age	Impairment	Household composition	Main informant	Identified health need
Sibongile	M	Mid 30's	Mobility (walks with crutches)	Head of household, married with young children	Self	Assistive devices: crutch ferrules
Nozukile	F	Early 40's	Mobility (walks with difficulty)	Head of household, unmarried, cares for siblings	Self	Pain, fatigue, chronic non-specific symptoms

Siphenathi	M	Mid 20's	Cerebral palsy, unable to walk, intellectual disability	Eldest of three children, mother is head of household	Mother: Mamthuli ¹⁸	Assistive device, medication for behavioural problems
Thembinkosi	M	Mid 30's	Hemiplegia, epilepsy, difficulty walking and using one arm	Lives alone	Self	Not currently seeking healthcare
Phindile	M	Mid 30's	Mental illness	Lives with brother, who is married with children	Brother and sister-in-law	Mental illness – defaulted on medication
Ayanda	M	Mid 30's	Mental illness	Lives with father	Father, self	Mental illness – defaulted on medication
Nocawa	F	17 years	Hearing impairment	Lives with mother and siblings, father works in Johannesburg	Mother	Hearing aids and ear health
Lindile	M	Late 40's	Hearing impairment	Head of household, married with four children	Wife, daughters	Not currently seeking healthcare
Luzuko	M	Mid 30's	Mental illness	Lives with mother, unmarried	Self	Mental illness – controlled on medication
Iris	F	60's	Paraplegia, unable to walk	Head of household, lives with daughter and granddaughter	Self	Not currently seeking healthcare

¹⁸ I have given names (pseudonyms) to family members in only two cases, both mothers of people with disabilities. Not only did they speak on behalf their children, but they played key roles in the stories and warranted recognition as 'main characters'. In other households, I have referred to family members by their relation to the person with a disability, for the reader's ease of reference.

Nolufefe	F	16	Cerebral palsy, intellectual disability, walks with difficulty	Eldest of four children, lives with mother, who is widowed.	Mother: Nontombi	Not currently seeking healthcare
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As can be seen, our sample included more males than females (seven males, four females), with the thirties age group most strongly represented (five out of eleven participants). There was underrepresentation of older adults, who may be expected to have a high incidence of disability, which may have been due to our informants' conceptualisation of disability as different to the usual processes of ageing¹⁹. We did however succeed in securing a range of impairment types (four with physical disability, two with sensory disability, three with mental illness and two with multiple disabilities), and household compositions, which proved to have significant impact on healthcare seeking. Three of the households included a child with a disability²⁰. The reasons for seeking healthcare varied widely, including both chronic and acute health needs, both related to their disabilities and otherwise. The services accessed (or at least sought) were also varied, including visits from *nomakhayas*, routine clinic care (acute and chronic), hospital outpatient visits to see a doctor, hospital admissions, and referrals to tertiary care. Only two participants reported contact with rehabilitation services. Other health services accessed included private general practitioners (GP's), private retail pharmacies, traditional herbs (both purchased and prepared for oneself), and consultation with a *sangoma* (traditional healer). Three participants described seeking healthcare outside the district in which they lived (excluding the tertiary referral centre).

3.4. Data generation

Data generation was organised around the production of case narratives for each of our eleven participants. Narrative interviewing provided the starting point for each story, and was subsequently supplemented with participant observations, follow-up interviews and key informant interviews (and in a few instances, document review). Contextual knowledge was sought through general immersion in village life, in order to deepen insight into the stories related by participants and key informants.

3.4.1. Data generation methods

Table 4 summarises the data generation methods and the types of data produced. These are explained in more detail below.

Table 4: Data generation methods and products

	Sampling	Data produced
Immersion in context	Everyday life in Kwabisi village, physical activities of daily	Fieldnotes

¹⁹ Interestingly, Gogo herself could have been considered eligible for the study, as she experienced serious mobility difficulties due to her age (early 80's) and arthritic knees. She did not seem to identify herself as disabled however.

²⁰ Although Siphenathi was a young adult at the time of the research, he remained highly dependent on his mother, and his story extended back to his birth with cerebral palsy. This was more like the story of a child with a disability than of an adult.

	living, attendance at local events	
Narrative interviewing	Eleven participant households	Fieldnotes Transcripts of debriefing conversations Annotated interpreted transcripts of isiXhosa language interviews
Participant observation	Healthcare seeking occupations, interactions in the interface between participants and the healthcare service	Fieldnotes Transcripts of debriefing conversations
Key informant interviews	Healthcare workers, particularly those directly involved with participants: <i>nomakhaya's</i> , clinic staff, hospital staff Community members able to shed light on local happenings (including Xaks, Gogo)	Fieldnotes Transcripts of debriefing conversations Transcripts of English language interviews Annotated interpreted transcripts of isiXhosa language interviews
Document review	Patient-held health records, including referral letters and reports Public documents in health service facilities, e.g. educational posters	Fieldnotes, photographic records of public documents
Reflective conversations and journaling	Social dynamics between researchers, participants and healthcare workers	Transcripts of debriefing conversations Reflective journal entries

3.4.1.1. *Immersion in context*

General immersion in the context is recommended to deepen background understanding and enrich interpretation in cross-cultural research (Smith 1999), and this was achieved through time spent living in the community, and taking part in local activities and events, from carrying water to attending funerals. This formed a basis for ongoing discussions with key informants, particularly Xaks, about social patterns and cultural meanings, as well as providing a backdrop to the stories we heard. Field notes and reflective journaling were used to record experiences and observations, which also drew in my previous experiences in this and similar settings.

3.4.1.2. Narrative interviewing

In the first visit to a household, participants were asked to tell the story of a recent (or past) interaction with healthcare services. The process of narrative interviewing as described by Greenhalgh (2006), was used as a framework. To support the telling of the story, probes were used for clarity and for further information (see Table 5). Initial interviews lasted between thirty minutes and an hour. Following each interview, a debriefing discussion was held between Xaks and myself, which was also recorded. This included clarification of interview content and reflections on the interaction and the story told. Further observations and reflections were recorded as fieldnotes, completed as soon after the visit as possible and used to plan follow-up.

Subsequent visits to participants were used to confirm and clarify the stories told, and to seek additional information where required. On some visits, other household members were present and were invited to contribute additional perspectives, or did so spontaneously. In our reflections on each encounter, the social context of the conversation was considered for its influence on content, and for what it said about underlying social patterns and structures.

Table 5: Probes for narrative interviews

	Questions
Starting question	Please could you tell us a story about a time you have gone to use the healthcare services, for example the clinic or the hospital? It can be something recent, or in the past.
Probes	<p>What happened beforehand that made you decide to go?</p> <p>What did you need to do in order to be able to do this? (for example, organising transport, organising someone to look after the children)</p> <p>What happened when you went?</p> <p>What happened next?</p> <p>What did you think about that?</p> <p>What did you do next?</p> <p>Where are you now, with the problem you had?</p> <p>What do you think you will do in future?</p>
Follow-up interviews	<p>Last time, you told us this story [recap]. Can you tell us more?</p> <p>What has happened since the last time we spoke? [use similar probes to first interview]</p>
Reflective questions	<p>If you could tell healthcare workers how to help you better, what would you say?</p> <p>How do you think your disability has made a difference in this experience of healthcare seeking?</p>

It became clear that people were not comfortable with some of the questions, and that question-asking in general could be experienced as suspicious or intrusive. I was aware that in this culture,

question-asking is not encouraged in children (Mandela 1995; Krog et al. 2009), and had experienced in the past how people resisted, or had difficulty, answering “why” questions. More abstract reflective questions were also challenging, and it was clear that constructs such as citizenship, and even disability, were not necessarily thought of here as elsewhere.

Building and maintaining trust depended on providing space for people to choose their own levels of response, and to evade probes where they so wished. In this socio-cultural context, it was unlikely that households would feel free to refuse participation openly, as this could be seen as inhospitable, and going against the endorsement of local leadership. A power differential existed between us as outsiders (particularly myself as a white, middle-class, urban academic and health professional) and people within this geospatially, culturally and socio-economically marginalised group. The political history of colonialism and Apartheid, particularly in this region, played a powerful role, and we needed to be extremely sensitive to subtle indications of discomfort and resistance, as an important part of the continuing consent process (Posel & Ross 2015). In all of these things, narrative emerged strongly as a safe and relatively natural form for data-generating conversation.

Developing an appropriate and sensitive approach to interviewing was both challenged and strengthened by the issue of language. Participants generally spoke no English, and interviews were conducted in the local dialect by the research assistant. I was able to follow to a limited extent, but relied mainly on Xaks’ interpretations. We prioritised keeping the flow of the interview over detailed in situ translation, and my capacity to participate in the interview was therefore limited. Interviews were audio-recorded with the participants’ permission. As Xaks became familiar with the topic, he was increasingly able to conduct the interviews without my input. This allowed him to shape the interactions according to local patterns of communication and social interaction, which tended to yield richer data than the original interview guide, as well as teaching me about ways of communicating in this context. A large part of every conversation was in fact tacit, made up of understatement, inference and indirect approach to most topics. This subtext was only accessible to me through Xaks, and led to the development of a co-analysis process which in itself was a layer of data generation.

3.4.1.3. Participant observation

Where the story narrated was a recent or current one, we sought opportunities for participant observation, as well as complementary interviews with involved healthcare workers. Permission for both was requested from the participant before these were followed up, and the appropriate procedures followed with the health facility concerned.

Participant observation is conventionally seen to encompass a spectrum, ranging from ‘pure observer’ to ‘full participant’ (Spradley, 1980). The interpretivist stance does not allow for the former, as discussed above, while the latter presents problems for ethnography in healthcare settings specifically, where it is impossible for the researcher to take on fully either a patient role or that of a healthcare worker. Wind (2008) proposes the alternative concept of “negotiated interactive observation”, emphasising the tensions of the researcher role in a healthcare setting, and the ongoing process of negotiating relationships and access to spaces. A former nurse now working as a medical anthropologist, she describes the value of her clinical background in her work, at the same time as her now fundamentally different positioning, particularly in relationships with healthcare staff and patients, and her own responses to the setting. This was true in my experience in this project, with my previous experience as a clinician in the same health system proving both useful and problematic. It afforded me a degree of “insider” knowledge, both clinical and organisational, but also meant I

entered the space with preconceptions about what took place. Practices of reflexivity were critical in both challenging and utilising this knowledge.

A major challenge posed by this positioning lay in witnessing the frequent failure of healthcare services. As reflected in Table 3, few of our participants had satisfactory access to healthcare when we met them. Our help was often requested in writing referral letters²¹ or advising on alternative sources of support, while at times we initiated attempts to solve difficulties, based on knowledge of how the system could or should be functioning. Accustomed to a clinical role, which had often required unconventional action and considerable effort to overcome obstacles, I found it extremely difficult to inhabit the researcher role without becoming more involved in people's stories.

Our interventions therefore became part of the unfolding story, and I chose to problematize the experiences as additional data. Although this might have been considered an unnatural disruption of the "field", we were strongly aware that our presence, even without direct involvement, could cause such a disruption. Refusing requests for help from our participants was morally and ethically unacceptable, and would have violated the obligation for reciprocity inherent in the relationship.

The recording of our participant observations, or negotiated interactive observations, was in field notes, as well as in recorded debriefing conversations with Xaks. Key informant interviews after the fact, with involved healthcare workers, added a further layer to the story. Descriptive field-notes captured unfolding events, but also observations of the participatory spaces and the occupations of health service access. Hocking's (2009) proposed schedule for describing occupations was used as a starting point for observations, and informed the framework I developed for observing participatory spaces.

Table 6: Describing occupations (Hocking, 2009)

Capacities, knowledge, attitudes and skills
Who participates, and with whom
What is done, and the rules, norms and institutions that shape this
Location, space, objects and resources
Temporal aspects: season, date and time, frequency, how long it takes, routines and sequences, links to past and future
Results, impact or outcomes
Meanings of the occupation for different actors, and how these are shaped
Sociocultural, political, economic, geographic and historical context
Impact on human health

²¹ While we had no official capacity to make referrals, in this setting such a letter could lend real weight to people's applications for services. We heard many stories of participants being turned away from services (including home affairs, social development and social security) to which they were entitled as citizens, on the whim of capricious officials. Both public service and local culture were heavily hierarchical, and poor people with little education had little power to leverage their rights.

Table 7: Observing and describing participatory spaces

Aspect of space	Examples
Physical features	Building structures; physical accessibility equipment and resources, qualities of temperature, smell, visual appearance, noise, physical comfort/discomfort; division of spaces within facilities; signage and information on display (e.g. health education posters, official notices)
Temporal features	Daily and weekly cycles, experiences of time for different actors, routines, time constraints on tasks, how is time divided and used, relation to past and future events
Functional or task features	Purpose of spaces, activities carried out, skills and knowledge needed to negotiate the space
Linkages to other spaces	Proximity to actors' life spaces, links with other parts of health service, costs of arriving here, accountability, influence of provincial and national policy
Social features	Roles, relations between actors, hierarchy, attitudes towards others, expectations, rules (formal and informal), spatial features, juxtapositions, e.g. waiting for clinic care with neighbours
Relations between aspects of space	How does the physical space fit with purposes? How are tasks modified as a result of other dimensions? How is experience of the space affected by other spaces and experiences?
Interpretive questions	What is this space an opportunity for? What are the potential actions and possibilities within the space?

3.4.1.4. Key informant interviews

During or after such observations, key informant interviews were arranged where possible to obtain healthcare workers' perspectives on what took place. These were audio-recorded with permission. Additional conversations with Xaks, Gogo and others served to deepen understanding and test interpretations of our observations.

3.4.1.5. Document review

Document review was used in a minor way, to supplement contextual understanding or participant narratives. Patient-held healthcare records offered useful supporting information for the stories related (see for example Nozukile's story), particularly as I was able to interpret these from an 'insider' healthcare perspective.

Public documents available or on display in health facilities added an 'official' voice that often contrasted significantly with the context in which they were observed. Examples included posters in waiting rooms providing information about patient rights, government policy or health issues. These were photographed for reference purposes, and also included in fieldnotes.

3.4.2. Data generation process

Qualitative research is an emergent process, with a large degree of uncertainty in both unfolding events and data content (Major & Savin-Baden 2010). This is due both to the exploratory nature of much qualitative work, and the complex social environments in which it takes place. This was certainly the case in this study, and flexibility and ongoing adaptation of plans and activities was essential. Constant reflection about the process was needed, with a critical stance towards assumptions and methods.

Data generation and analysis took place in an iterative manner, with analysis beginning in the field and informing the next step of data generation (Flick 2013). The overall process of data generation was organised into four "rounds", interspersed with periods of data management, review and preliminary analysis, which then informed the subsequent round of fieldwork. These are described in Table 8.

Table 8: Iterative data collection and analysis

Round	Activities	Time period	Completed by
Round 1	Community entry Immersion in village life Recruitment of eleven participants First round of narrative interviewing and participant observations	March – May 2013	KS, XD
Preliminary analysis: round 1	Review professionally translated transcripts Compile initial case stories, descriptions of participatory spaces and occupations Identify gaps and follow-up questions, prepare interview schedules Round 2	June – July 2013	KS
Round 2	Follow-up interviews and key informant interviews as per prepared schedule	August – September 2013	XD
Preliminary analysis: round 2	As for round 1 data Compare data generated with research objectives to inform round 3	October – December 2013	KS
Round 3	Reconnection with stakeholders Follow-up interviews, participant observations	February - March 2014	KS, XD

	Respondent validation: group discussions with participants and healthcare workers Co-analysis process developed and tested on round 3 interviews		
Preliminary analysis: round 3	Map data, compile case stories and descriptive summaries Co-analysis of rounds 2 and 3 Prepare schedule for final follow-up interviews and checks	March – July 2014	KS, XD
Round 4	Final interviews and follow-up as per schedule	July –August 2014	XD
Preliminary analysis: round 4	Co-analysis of round 4 data, progressing to reflection on entire body of data	September 2014	KS, XD

KS = Kate Sherry; XD = Xaks Dabula

3.4.3. Data management

Fieldnotes were typed on a password-protected laptop, using Microsoft OneNote, which allowed for organising sets of entries according to case and topic, and for cross-referencing between entries.

Audio-recorded interviews were downloaded and interviews held in English were transcribed by the researcher. Files were stored on the laptop and backed up in the cloud, both password protected. Identifiers were chosen for each participant to protect their identities. Texts were cleaned and annotated for clarity and organised into case folders by participant (including field-notes). Schedules of completed data generation episodes were kept to maintain a 'map' of the data and help with planning.

3.4.4. Interpretation of isiXhosa/isiBhaca language interviews

The first round of interviews held in isiXhosa were sent for translation and transcription by a professional translator. However, on attempting to analyse the transcripts, I realised that the text alone provided extremely limited information, and that given my lack of background understanding, I could not safely make any inferences at all from what was said. After some experimentation, Xaks and I developed a process of simultaneous interpretation and transcription, which incorporated an important layer of analysis. While Xaks was not trained to provide a verbatim English translation of the conversation, he was able to add rich information about non-verbal dimensions of what had passed, as well as cultural insight into meanings and events. He also provided an invaluable sounding-board for interpretations, and began to contribute his own. These conversations were increasingly wide-ranging, and became a shared sense-making process through which we both grappled with the research question, and broader questions about our respective world views and experiences. Notes on these discussions were recorded as part of my transcriptions of the original interviews, and the texts analysed as additional data.

3.4.5. Rigour and data quality

A broad range of constructs and approaches are encompassed in discussions of quality in qualitative research, and there is a need for matching quality definitions and methods with the purpose and nature of the research project, as well as with its philosophical stance (Savin-Baden & Major 2013)

Contextualised case study research has an important place in HPSR, although this is not always well understood in a field dominated by the biomedical paradigm, which relies on statistical generalisability from large samples (Gilson et al. 2011). The national and international relevance of the research question has been demonstrated in Chapter 1, and the methodology aimed to achieve analytic generalisability, through an authentic and credible capturing of this particular case, and a rigorous analytical process.

Authenticity was seen as the requirement of the presented case to “ring true”, and to present the voices and experiences of the participants vividly and as close to how they experience and express life as possible. While the ontological and epistemological stance described above does not admit perfect knowledge, authenticity was sought through triangulation of data sources, prolonged engagement in the field, peer debriefing, and co-analysis (see below) (Savin-Baden & Major 2013). I also needed to build in practices of reflexivity, i.e. interrogating my own place in the events and in their interpretation, including the influence of positionality, power relations and personal and professional values brought to the research (Duncan & Watson 2010; Cousin 2010). Throughout the research, I accessed a variety of spaces for reflection which afforded opportunities to consider these questions from different angles (Kuntz 2010). A bracketing interview with my supervisor at the beginning of the study clarified my starting points for the research, as set out in chapter 1. During fieldwork, I used journaling to reflect on unfolding events and emerging interpretations, as well as to bracket assumptions and value positions as they surfaced. Peer debriefing took place with Xaks on a daily basis, often informally as we discussed what had happened during data generation. While in the field, I also sent written summaries of activities and emerging insights to my supervisors in Cape Town, who gave feedback in verbal and written form. Returning from time in the field to the familiar setting of my home in Cape Town provided space for deeper reflection, and even more so a period of three months spent as a visiting scholar in the Netherlands during the analysis phase (Kuntz 2010).

Respondent validation or member checking is a commonly cited means of ensuring closeness of the findings to participants’ experiences (DePoy & Gitlin 2011). Two group discussions were held during my second fieldwork visit, one with participants and one with staff at the local clinic. Their aim was to present our initial findings for participant feedback, and to elicit further reflection and discussion. These events proved difficult to organise and to facilitate, for a number of reasons. There was evidence of ‘research fatigue’ among both groups, which affected engagement. It also became clear that neither Xaks as facilitator, nor group members, understood the format and purpose of the sessions, despite my attempts at preparation and explanation. There were also difficulties with understanding the more abstract questions posed²². Despite not completely fulfilling their intention, these discussions did serve to confirm previous observations, particularly about methodological issues in this context.

Respondent validation of our final interpretation and presentation of findings was problematic, both practically and epistemologically. Firstly, most participants did not speak the language used in my text,

²² For example, when I asked participants to reflect on who held power when they engaged with healthcare workers, I was met with complete silence. Xaks later explained that the word “power” was difficult to translate, because its direct correlate, *amandla*, was primarily associated with the ruling ANC and the struggle against Apartheid. He said, “They can think, is Kate working for the ANC?” Such complexities of language were unforeseen, and inaccessible to me at the time.

i.e. English. The research process itself had made it clear how language contained within it the cultural and knowledge frameworks of the speaker, so that simple verbal translations across language boundaries could convey very little of the meaning (Cousin, 2010). The findings were also explicitly my own interpretation of the data, shaped by my own questions and concerns. This meant that as a text, they would not necessarily be recognisable or meaningful to those whose stories were woven into them. At the same time, claiming the stories as my own constructions and making this process visible (or audible) shifted the need to prove concordance between participants' perceptions of the data and my representation.

The interpretive paradigm does not try to prove confirmability of the findings (i.e. the possibility of others reproducing or independently verifying the findings). Because of the role of the researcher's own actions, interactions and interpretations in constructing knowledge, as well as the particularities of time and context in this process, it would be impossible for anyone else to recreate the same experiences. A more appropriate goal was to establish credibility, i.e. to persuade the reader that the research, and myself as researcher, could be relied upon as a source of knowledge. Credibility was sought through clear exposition of method, thick description of context and data. This also contributed to transferability, by providing explication of the assumptions and conditions underpinning the study (Savin-Baden & Major 2013).

Together, these measures provided the basis for generating authentic, credible and rigorous data. The following section will describe the processes of analysis and interpretation.

3.5. Data analysis & interpretation

Analysis in fact began in the field, as the data emerging shaped ongoing decisions about how to proceed, and initial impressions and ideas were developed (DePoy & Gitlin 2011). Once data generation ended, analysis and interpretation proceeded in four key stages, although there was overlap between these over time, and returns to earlier stages as needed. Atlas.ti software was used for coding, in combination with manual methods of mapping emerging categories and themes.

Stage 1: Descriptive analysis

The first level of analysis included immersion in the data, and a process of data reduction, compiling each case story with all its various sources of data (Flick 2013). From the stories, I then produced detailed descriptions of healthcare seeking occupations and participatory spaces, as per objectives 1 and 2. Throughout this process, memos were created to note connections across cases, potential themes and emerging theoretical insights.

Stage 2: Co-analysis & interpretation

The second level of analysis took place in the collaborative interpretation process developed with Xaks, as described above. Taking a section of the data, namely the isiXhosa interviews from rounds 2-4, we used the process of linguistic interpretation to delve deeper into the social dynamics and unspoken content in each encounter. Being both well immersed in the data at this point, our conversation went beyond the immediate recordings to draw together trends and themes across the whole body of data. Where researchers from privileged backgrounds are brought into contact with communities who are marginalised, whether due to race, class, geospatial location, gender or disability, interactions arise which provide opportunities for the former to reflect on their assumptions and worldviews (Bozalek 2011). The collaborative relationship with Xaks was both a source of such experiences, and a space in which they could be discussed and learnt from (Ropers-Huilman & Winter 2010).

Table 9 presents the framework for the co-analysis process.

Table 9: Key questions for co-analysis

Focus of interpretation	Purpose	Probes (examples)
The research encounter	Interpreting the conversation (verbal and non-verbal content)	What did she mean? (offer potential interpretations) Why was this said in this context at this point? How did this link to other statements or events at other times? What was not being said?
	Unpacking language use	What word was used to express that? How else is that word (or expression) used? What was the significance of that linguistic choice?
	Understanding co-researcher choices/??	Why did you ask that question at that point? What made you decide to visit/not visit? How did people respond to us as researchers?
Participatory spaces	Understanding choices and possibilities for action	Why did they do this/not do that? What else could they have done? What would have happened if...?
World view/ frameworks of meaning	Surfacing world view	How does this link to other behaviour we have observed? How do people see this issue? What are the customary ways of dealing with this thing?

Stage 3: Narrative synthesis and creative re-presentation.

At stage 3, I returned to the narrative dimension of the data. It was clear that the simple descriptions produced in Stage 1 failed to capture the richness represented in the unique unfolding of each story over time. The types of data we had collected went beyond the verbal performance of story-telling, so that each case story was in fact multi-vocal and richly contextualised. The challenge was to re-present these stories for an 'outsider' audience, capturing the nuances of situations, as well as the crux or plot of each story, which itself emerged from a process of interpretation. Writing qualitative texts is increasingly recognised as a generative and interpretive exercise in itself (Holley & Colyar 2010). An analysis journal was used to record and bracket insights, questions and emotional responses

during the narrative construction process, and different versions of the stories were shared with my supervisors and other readers as they were created (Richardson & St Pierre 2008)

A critical intention of the research was to allow the voices of rural people with disabilities to be heard (McKenzie et al. 2014; Ropers-Huilman & Winter 2010; Smith 1999). Questions of who may speak for whom are highly sensitive, particularly in a post-colonial context with marginalised groups (Bozalek 2011; Smith 1999; Ropers-Huilman & Winter 2010). I chose to position myself clearly as narrator in order to make my own subjectivity transparent (Cousin 2010). Verbatim quotes were used to reflect the different voices in part, but needed to be carefully contextualised to bring out meanings beyond the explicit. Additional data generated in stage 2 was incorporated in both the body of the story and in footnotes, also allowing Xaks' voice, as co-researcher, to emerge. My own difficulties with "hearing" what was really being said, often tacitly rather than explicitly, have already been described. This stage of analysis required deeper immersion in the data, with a critical ear for what was not being said. As I became more familiar with how people customarily spoke, it became easier to identify unusual moments in our conversations, and to follow a sense of discomfort or bafflement that sometimes surfaced. These moments, as a form of negative case analysis, became a focus for further reflection, and often triggered key insights, both into the participants' world and my own contrasting perspective.

In addition to the process of constructing each story, I began to make choices about which stories to include in a presentation of the findings, drawing links between those that emerged, and selecting a combination which best captured the data in its entirety (Holley & Colyar 2010).

This stage of analysis sought to address the first part of the research question, namely to capture the nature of the engagement between rural people with disabilities and their families, and healthcare workers. The end product is presented in Part 1 of Chapter 4.

Stage 4: Thematic analysis/theory-building

The final stage of analysis returned to the second half of the research question, i.e. the potential offered by the interface for more responsive healthcare and more engaged citizenship in health (also reflected in objectives 3 and 4 in the research protocol). The stories constructed in Stage 3 were the departure point for this level of interpretation, although constant comparison with the full body of data was continued throughout. The question, "What is this a case of?" guided a thematic analysis, producing a set of core themes and their composites of categories. Relationships between these were then interrogated, with comparison across the eleven embedded cases allowing for pattern matching and negative case analysis (Flick 2009). Manual story-boarding was used for these processes, and led to diagrammatic representation of the final themes. The developing themes were triangulated with the literature in the light of the research question and underpinning assumptions, in an iterative process.

3.6. Ethical considerations

The ethics of cross-cultural research, particularly with vulnerable and marginalised groups, are complex and contested. Formal requirements posed by ethics boards are often insufficient for, or even at odds with, the requirements for ethical behaviour in the field (Posel & Ross 2015). For this study, all of our interactions needed to take account of the social, cultural and historical context, and the ways in which it shaped power relations between us and our participants. As Duncan and Watson (2010) attest, it was not possible to anticipate the potential risks and implications of the research process for our participants, and therefore ongoing dialogue and reflexivity were needed to identify and address issues as they arose.

Official permission for this study was obtained from the University of Cape Town's Health Research Ethics Committee (HREC no 569/2012, see Appendix A) as well as from the Eastern Cape Department of Health's research office (Appendix B). Spaces for ongoing ethical reflection and reasoning were created, which included my daily fieldnotes, the local research advisory group (see below), and my two supervisors, one of whom had extensive first-hand knowledge of disability research in this particular community. Most important however was Xaks' role as my guide, partner and co-researcher in the field.

3.6.1. Community entry

In this close-knit and traditionally structured community, processes of community entry were especially important. Our actions were highly visible from the first, and being seen to follow the correct procedures and show respect for social relationships was essential to our acceptance (Duncan & Watson 2010).

Following the previous research in the Kwabisi community, I was already familiar with, and to, local leaders and other community members. With the support of the local chief, known to all as 'Gogo', or grandmother, we were given an opportunity to address the local *imbizo*²³ in order to explain the project and formally ask permission from the community leadership, which they granted. Attending headmen, sub-headmen and heads of households were requested to share information about us in their locations, so that our presence would not come as a surprise or be considered suspicious. It was critical that we be known to have followed the correct channels in approaching the community, and for potential participants to know that their leaders had approved our activities. Local social structures render each household accountable to the leadership, and it is unlikely that any would have agreed to speak to us without this assurance.

More detailed accountability for our work was arranged with the advisory group established for the PPP project. Comprised of several elders (male), two women known to be active in the community, Gogo herself, and one person with a disability, the group had played a consultative and organising role in the previous project, and was reasonably familiar with research processes and disability issues in the area. Our proposed work was discussed with them in greater detail, and their input specifically sought concerning consent procedures and other ethical issues. They approved the overall approach, adding the request that we keep them informed about any households where neglect or abuse of people with disabilities was suspected.

During the first round of the fieldwork (three months), I lived in the location itself, in order to immerse myself more in village life, and build relationships in the area. Gogo offered me a room in her homestead, which proved important in demonstrating her sanction of the project, as well as affording me the protection and status of being considered a member of her household. I had the opportunity to attend community events such as funerals and leadership meetings with her, which both taught me a great deal about the context, and made me a familiar sight to people in the location.²⁴ This proved important in ensuring our welcome at the households we visited, and reducing any potential hostility to us as obvious outsiders. Xaks, who was already well known and respected in the area (although not

²³ Regular meeting of elders, headmen and subheadmen, as well as other community members, for the purpose of sharing news, making decisions, judging local disputes, and other community matters.

²⁴ I would also often be formally introduced at such gatherings, and my purpose in the area explained. On one occasion, an elder who thus introduced me, did so with the remark, "and you all saw her this morning, when she was gymming [running] in the location". Despite my sunrise start and the apparent quiet, the nods and grins of the gathering made it clear he was right!

a resident of this location), played an essential role in securing people's good faith and willingness to engage with us. His personal reputation aside, his status as a Bhaca himself was highly significant. Typical encounters in this and other African cultures begin with an exchange of genealogy: identifying one's father, other relatives and clan served to position one within the social structure, with the personal reputation of key family members playing an important role in how one is received.

Because we intended to collect data in health facilities (particularly the Kwabisi clinic and district hospital in Mt Frere), and to interview health service employees, it was necessary to obtain permission from the Eastern Cape Department of Health research office (see Appendix B). Once this was secured, we approached the district health manager and line managers for local healthcare workers. Letters of permission were obtained from the district manager, to show to the hospital and clinic managers to facilitate access, and interviews with staff were, where possible, agreed with their line managers in advance, and times chosen to avoid disruption of their duties.

3.6.2. Informed consent

Consent procedures required by the ethics board were based on biomedical research norms, and as such did not specifically address the social and cultural complexities of this research situation (Posel & Ross 2015). In this context, individuals do not necessarily hold the right to consent to their participation in research themselves (Duncan & Watson 2010), and negotiating consent at tribal authority level was a critical first step. At household level, permission needed to be sought from the head of the household. Identified households were approached for an initial visit, often with the referring *nomakhaya* in attendance. Xaks conducted introductions to ourselves and the research project, taking care to contextualise our visit in terms of the previous UCT research on disability in the area. The formal consent procedure included a summary of the research, translated into isiXhosa, which Xaks would read through and clarify, answering any questions (see Appendices C & D). Where the person with a disability was unable to participate directly themselves (for example due to mental illness or intellectual impairment), the caregiver and/or head of household would be approached as primary participant instead. Participants and other consenters were given the summary to keep, including our contact details. They also signed consent (using an "X" if unable to write their names, as some were illiterate), for record purposes, although were reminded on each encounter of their right to withdraw from the research at any point. Although none chose explicitly to do so, we were soon aware that some participants were unwilling to engage with us to any depth, tending to evade questioning with brief, superficial answers repeated over time. It was difficult in these cases to determine the most appropriate action, but we chose in general to continue to honour our relationship with them while withdrawing probing. We continued to visit these households when in the area, and followed the same procedures for termination at the end of the research.

Given the limited exposure of this population to academia and the use of research outside the participant population, we made allowance for ongoing conversations about the process throughout our engagement with each household, although this was often ambiguous and time-consuming. We also needed to address expectations of the research as they arose, for example by clarifying the limits of the help we could provide, as well as our own affiliations. For example, form-filling is often associated with government activities, and could lead to expectations of services to be provided.

The same consent procedures were used with healthcare workers, with the explanatory conversation adapted to respond to their specific questions and concerns. As described above, formal approval from line managers was essential, as was demonstrating sensitivity to the demands of their work, which often meant keeping interviews brief.

3.6.3. Confidentiality

Given the physical structure of most homesteads (typically single-room *rondawels*²⁵ or four-walled dwellings), private conversations were difficult to arrange, and we were often joined by curious neighbours or other incidental visitors²⁶. It is likely that requesting confidential interviews would have been considered suspicious in this context, and we chose instead to be guided by our participants in agreeing to proceed or reschedule the interview. It was also necessary to remain sensitive during the conversation to potential discomfort, and to withdraw questioning where appropriate.

In the recording and reporting of data, pseudonyms were used for all participants, and details of location and other identifiers were altered as far as possible to ensure anonymity. Conflicts arose where we encountered suspected abuse or neglect of a person with a disability. Our ethical duty as researchers, my legal duty as a healthcare worker, and our agreement with the community elders, all required us to report such instances. Unexpected complexities arose however when we had to discern neglect from unavoidable deprivation due to the context of poverty. In the case of one family, our intervention unintentionally exposed them to social risks we had not foreseen, while failing to change their situation due to the inadequacy of existing services.

3.6.4. Risks and benefits for participants

As illustrated, risks for participants arose in the course of the research which we had not anticipated, and mainly related to people's social standing and relationships in the community. It was difficult to gauge how neighbours viewed our visits, and we were aware of the perceptions that as outsiders, we brought financial benefit to the household. In this cultural setting, equal treatment of all is considered essential, and people are expected to share anything that they receive, especially with their extended family members. We became aware of the potential for jealousy of our participants, which might expose them to harm. Continual engagement with community leaders and official figures such as the *nomakhayas* and community development workers, was one means to detect problems and correct misinformation.

Participants were not paid for their time, although we covered transport costs when they met us outside their homes, and gave small gifts of groceries when data generation ended. We also undertook to assist in any way possible with their access to services, writing referral letters, discussing cases with the clinic manager, sourcing support in town and further afield, and providing advice or information. In a few instances, we accompanied people to seek health services, which might include driving them

²⁵ Round hut, usually built from home-made mud bricks with a thatched roof and traditionally a cow-dung floor. Often five metres or more in diameter, such a building could serve as kitchen, living room and bedroom for up to eight or ten people. One homestead might have two or more *rondawels*, and/or additional four-walled rooms with corrugated iron roofs, known as "flats", to house additional family members. Homesteads usually also include the *kraal* (livestock enclosure) and sometimes a maize patch or vegetable garden. Many activities take place in the open, either in the yard surrounding the buildings (e.g. cooking on a fire, washing dishes and doing laundry), or in the surrounding communal land (e.g. fetching water or wood, herding animals or going on foot to catch public transport, visit neighbours, etc). All of this contributes to a very public "private" life.

²⁶ In this culture, it is very important to maintain an "open door" at the home: signifying both the value on hospitality and the suspicion of any kind of secrecy. This norm made it very difficult for participants to refuse our requests for interviews overtly.

there, and assisting with obtaining the correct help. These were treated as experiences of participant observation (discussed further below).

3.6.5. Ethicizing in uncertainty

Duncan and Watson (2010) propose three processes through which researchers can continually work out the ethical, moral and personal dilemmas that arise in the course of cross-cultural research with vulnerable people, namely transparency, reflexivity and representivity.

Transparency is the requirement to be honest with participants about research intentions, purposes and limitations, including our own struggles with knowing how to act. This was enacted not only with households and individuals, but importantly with community leaders and healthcare staff as well. This required ongoing communication and working on relationships, and was both time-consuming and energy intensive. Our success in communicating what we wished to was always partial, and it became clear that our perceived actions were judged with more weight than the verbal explanations we tried to give.

Reflexivity involves questioning how knowledge is produced through the research process. This included the responsibility to interrogate my own assumptions and ways of thinking about things, and how these might be based in enculturation as a white, urban English-speaking South African woman, an occupational therapist and a health researcher. The imposition of Western cultural frameworks on indigenous populations has been widely problematized (Smith 1999; Owusu-Ansah & Mji 2013; Kinsella 2012), as has the imposition of 'able-bodied' ways of seeing the world on the experiences of people with disabilities (McKenzie et al. 2014). Immersion in the setting, combined with ongoing reflection and conversation about what was happening, were critical to reflexivity. Xaks was an invaluable mediator, being familiar both with the research world (to some extent) and the world of our participants, as were Gogo and several others. Reading African literature and philosophy also helped me gain new language for thinking about what emerged (Duncan & Watson 2010).

Representivity concerns the ways in which knowledge is constructed and articulated to include the voices of groups who usually remain unheard. Dealing sensitively with language proved highly complex, and again, involved the research partnership in a constant process of mutual interpretation. Writing the research report in the first person, and so claiming my particular positionality within the story, aimed to allow my voice to be separated out from the voices of others. Using direct quotes and accounts of conversations, including the layered interpretations developed through multiple data sources, allowed me to capture some of the complexity and ambiguity of the participatory spaces. It was critical to portray the contradictions and areas of messiness which arose where actors' viewpoints and interests clashed, as well as the places where my own discomfort and uncertainty arose (Duncan & Watson 2010).

Transparency, reflexivity and representivity were essential processes in dealing fairly and truthfully within the research setting. Most important however, was coming to understand the responsibilities and expectations built into the relationships we formed with the community.

3.6.6. Right relationships

The Xhosa (and Bhaca) worldview is premised on social harmony, solidarity, and the honouring of relationships (Cornell & van Marle 2005; Engelbrecht & Kasiram 2012). While I knew this from the outset, I continued to learn constantly through the research what this meant for our practice, leading eventually to a dramatic shift in how I saw what happened. While my Western research training emphasised correct words and procedures, our participants were primarily concerned with how we

demonstrated the honouring of relationships. The two proved often to inform diametrically opposed actions. While from my perspective, directness and clarity were part of showing trustworthiness, in this community they were mistrusted and even found offensive. Actions held far more weight than words, and appearing to be in a hurry to pursue one's own agenda could demonstrate a lack of value on 'being together'. Over time I came to appreciate the weight of what people offered by their simple presence with us, regardless of what was said.

Fortunately, Xaks was able to guide and mediate our relationships, as I was often completely unable to judge the correct course of action. Reciprocity, value placed on 'being together' and a respect for custom and hierarchy, all emerged as central. It became clear that terminating the relationships once the data generation was complete would be inappropriate, demonstrating that we had come only to take what we needed from the community. Through Xaks, we have maintained a presence in the community, and he has become a source of information and advice for the households, as well as providing practical assistance on occasion. Ethical practice in community research dictates a return to the field at the conclusion of the project to share feedback with participants. At the time of writing, this was being planned.

3.7. Summary

This chapter has demonstrated the appropriateness of a qualitative, ethnographic case study methodology for the purposes of this research, and has discussed the details of the approach taken. An interpretive stance formed the basis for cross-cultural sensitivity and learning, and the collaborative partnership with Xaks as co-researcher and cultural broker proved essential, for both meaningful interpretation of data, and ethical conduct of the study. Continuous reflexive practice, which acknowledged the socially co-constructed nature of the data, underpinned the research process.

Chapter 4: Findings

Introduction

This chapter seeks to describe and interpret the nature of the engagement between our participants and PHC workers. The first three objectives of the study are addressed, i.e. to describe the participatory spaces and the occupations unfolding through them, and to interpret these in terms of the PHC principle of community engagement. Part 1 captures engagement between rural people with disabilities and healthcare workers in the PHC interface through a series of stories. Part 2 interprets these findings in terms of emerging themes.

Part 1: Five stories of engagement

As we engaged with our eleven participant households over time, a rich array of stories came to light. Some were about engaging with healthcare, some were about choosing not to do so, and still more unfolded in our own relationships with these people over time. We became part of the healthcare seeking quest on purpose on some occasions, while on others, our presence unwittingly played out the dynamics of assumption and resistance reflected in the interface. Each case was built up carefully through multiple interactions and reflective discussions, with insights developed through one story feeding into the others. As mentioned in the previous chapter, not all of our participants were willing to engage to the same depth, and some stories remained sketchy and cryptic. In seeking to present the scope and richness of the data, I have chosen to tell five stories here in some detail. While these feature the five households we came to know best, I have attempted to weave other participants' narratives into their telling, so that together they convey a sense of the whole. My own story of trying to uncover and understand what was happening in the interface, is woven throughout.

4.1.1. Nozukile: quiet not passive

I began this study with the idea that people were perhaps too accepting of poor treatment from healthcare workers. Having spent time as part of the system myself, I was familiar with what a typical consult with a nurse, or particularly a doctor, could look like, and I had my own ideas about how people could challenge the kind of dismissiveness and inadequate attention they might receive. Nozukile's experience with healthcare seemed to capture the problem well, and allowed me for the first time to hear the voice of the person who undergoes this experience. Gradually, as my ears became attuned to what she was (and wasn't) saying, my understanding of her behaviour shifted, and I began to question the assumption of what patient empowerment might look like.

Nozukile is a woman perhaps in her early forties, pleasant and softly spoken. She is unmarried, living in the family homestead with her two younger siblings, since her mother passed away a year or so previously. She was born with "pigeon toes", so walking is painful and slow, but we have never heard her complain, and she runs the household like any good Xhosa woman, and also sews clothes to sell to her neighbours.

This is the story she tells us:

NOZUKILE: “From 2008, I started to have a problem with my heart, that beats fast, my arms become tired, and I have a headache and cramps, more especially when I wake up in the morning. And I would go to the clinic.²⁷

“We would walk up to the clinic, go to the scale, take the BP [blood pressure], and see the sister. She would give me pills like Brufen²⁸, B-Co²⁹ and Panado³⁰. I would feel better for some time and then this illness would come back again, although sometimes I still took the pills. The clinic would give me a letter and send me to Madzikane [hospital]³¹. And I would be given the same pills: Panado, B-Co and Brufen. The doctor would say he does not see anything wrong with me and he will not treat me for something he does not see.

“One doctor I saw at the hospital, told me that they do not have a pill for the heart. So I must buy a small paper bag from Just On³², breathe in it and exercise³³. She did not even touch me or give me any pill. I went to the pharmacy to buy some pills.

“The situation got worse in January 2013, because I could not walk and we had to ask for a neighbour’s car to take me to the clinic. A letter was written and we were sent to hospital. We went there in the morning, and we stayed the whole day, till 16:30 p.m., waiting to see the doctor. Then we were told it is closed, we must come the next day.

“We met the doctor the next morning... and he gave me Brufen, B-Co and Panado.”

Her tone is mild, but there is a trace of derision when she comes to this last phrase. It is symptomatic treatment: an analgesic, an anti-inflammatory, and a vitamin supplement for good measure – a catch-all script for health-care workers when no obvious diagnosis presents itself. The same tablets are doled out to hundreds of primary care attendees daily. It is a commonly voiced assumption among health-care workers, particularly where less educated populations are seen, that one must at least give “something”. The patient will only be satisfied if there is a pill. But she knows that this is “something” for the sake of something, and nothing more.

The story is a familiar one to me: middle-aged woman repeatedly seeks help for a long list of “non-specific” complaints. Healthcare workers across the country have various terms for it: “GBP” (generalised body pains), *umzimba wonke* (“whole body”). In my previous job, we called it “GOLP”: “generalised old lady pains”. Nurses in this area also routinely include “jugular pain” in their history-taking: a locally endemic complaint, which mystifies and infuriates non-Xhosa healthcare workers for its apparent lack of medical grounding. In my clinical role, I had frequently seen how such patients were resented by busy primary care workers (including myself), and the kind of ‘brush-off’ prescription

²⁷ This story is an edited version of the first account we heard from Nozukile of her illness, edited to highlight the “refrain” of the prescription. Omitted sections are not marked with ellipses for the sake of continuity; the order and coherence of the story is maintained.

²⁸ Ibuprofen, a common anti-inflammatory

²⁹ Vitamin B supplement

³⁰ Paracetamol

³¹ District hospital, 45km from her home, in the nearest town

³² Local cosmetics chain store

³³ This strange-sounding suggestion indicates that the doctor thought Nozukile was experiencing panic attacks. There is irony in the sense that he/she was considering an emotional or psychological dimension to the complaint, but proceeded to handle the consultation in a way that did not engage with Nozukile’s emotions or mental health at all. Giving a practical detail like going to a particular shop in town to obtain the paper bag, implied some attention to context and practicalities, but Nozukile’s overriding experience seemed to be that the doctor did not understand her problem at all.

she described was typical. A comment in my field notes after the visit demonstrated vividly why this is so:

“Part of me had the usual scepticism about what was real or imagined, and how serious it was.” (Field notes, round 1)

“Real” versus “imagined”: the healthcare worker’s typology. “Real” means that it can be measured and described using medical tests, and that a physiological aetiology can be identified, preferably one for which an allopathic treatment exists. “Serious” refers to the clinical prognosis, the amount of (measurable) physiological or anatomical damage the pathology is likely to cause without treatment. An illness cannot be “serious”, without being “real”, and vice versa.

The implication of presenting at a healthcare facility with an “imagined” and “not serious” complaint, is that you are wasting the healthcare workers’ time. Women with “GOLP” often accompany their symptom reports with dramatic sighs and groans, which earns them the label of “attention seeking”, and detracts from their credibility, with Western-trained healthcare workers in particular. The “script” that is being repeated by successive clinicians is not only the prescription for medication, but also the diagnostic and behavioural formulae tied up in the response to this category of patient.

On this occasion, however, I am listening differently. Forty-plus kilometres from the hospital, and a decent walk on rough paths from the public transport to get there, I have a physical sense of the investment behind going to see a doctor, and even more so for someone who struggles to walk. She has described the time commitment (close on two days for a single consultation³⁴), and at other points mentions the cost: not only her own taxi fare, but that of a relative or neighbour accompanying her when she is too ill to go alone. The “neighbour’s car” to get to the clinic in January 2013 would not have been a favour, but a rental, probably for more than the taxi fare to the hospital. Sitting in this sparsely furnished home, it is clear that money is no small concern, and there is no question that these repeated trips were taken lightly. Nozukile’s sewing business brought in a small amount of additional cash, but she explained that when she is ill, she is unable to work more than a day or two in the week.

Later, I write in my fieldnotes:

“As a clinician, I settled immediately into my accustomed role of teasing out the history, and trying to scan for what might be wrong, and what they might have missed. It pressed my buttons to see page after page [in her clinic book] of “jugular pain”, palpitations, headache, etc - I just wanted to understand what would help.” (Field notes, round 1)

In this province, the outpatient medical record is “patient-held”, and this is what I am reading now: a worn, dog-eared booklet, often a cheap exercise book cut in half, layered with the stapled, carbon-copied, and often fairly miscellaneous souvenirs of past medical examinations, laboratory tests and hospital admissions. On the pages of the booklet itself, cursory and often illegible entries record the formulae of health-care workers, which reduce the holder to salient symptomatic features on a given

³⁴ Public transport from the location to town leaves first thing in the morning, consisting of a government bus, and one or two *guru-guru*’s – privately owned pick-ups (or *bakkies*), with makeshift seats in the back. There is seldom other transport until the same vehicles return at the end of the day. The journey takes one and a half to two hours, in very cramped conditions and on a rough road, costing R40 per person. Wheelchairs are charged a full additional fare, if the drivers agree to carry someone with a disability at all. Villagers arrive at the hospital after eight in the morning, where others would have begun queueing in the outpatient department by 6am. At 4.30pm, the patients who had not yet been seen would be sent home and told to return the next day, with a number indicating their place in the queue. Nozukile fortunately had a relative living near town, and would stay over with her when this happened, but it still meant additional taxi fare to and from the house.

day. The book is handled with reverence by its owner, often kept safely in the home under a mattress or in a suitcase on top of a cupboard, along with birth certificates and other precious documents.

The patient-held record has layers of irony for me. The holder literally carries “her” story with her, and is lectured regularly on her responsibility to guard it carefully. Officially, a healthcare worker will not see a patient without it. But it is almost unintelligible to the holder herself, not only for the technical language and the abbreviations, but also for the renowned scrawl of doctors, the omissions, and the haphazard addition of extra papers (often out of chronological order or missing pages). Its words are those of the medical world, but its surfaces bear the stain and wear of crowded taxi journeys, long hours waiting on benches, and life lived far from the reductions of clinical terminology. And in contrast to the faithful guardianship of this strange record over years, most entries contain a kind of amnesia: few clinicians read more than the previous one or two visits’ notes.

What I am seeing here, in Nozukile’s descriptions of her healthcare visits, the notes in her clinic book, and reproduced in my own habit-driven responses to her story, is a particular viewpoint held by health-care workers, a clinical gaze. It skims her symptoms and quickly categorises them as insignificant, labelling her as another complaining woman, a case of “generalised old lady pains” or *umzimba wonke*, with the attendant judgments of attention-seeking or over-reacting. This gaze is reductive: not only is the minimal necessary information collected and considered, but the context for her visit is also ignored, not only the physical journey but also the evidence of repeated visits over time. The healthcare worker responds to her with a formulaic script and little more.

But Nozukile is far from blind to the kind of care she has been receiving:

NOZUKILE: What I also think is, maybe when the doctor looks at the card and sees that the nurses have given me these pills, he thinks he must also do the same. And also when the nurses look at the card and see that the doctor has given me these pills, they think they must do the same.

INTERVIEWER³⁵: Does anyone [at the clinic/hospital] ask you whether these pills are helping you or not?

NOZUKILE: No one has ever asked whether they are helping me or not.

To me, this seems crazy. Do the healthcare workers not realise what she has gone through to get there? That this kind of effort, repeated over years, can only mean an illness that is, for all practical purposes, both “real” and “serious”? I put myself back in the shoes of the nurses and doctors, facing the heaving outpatients’ waiting area, the crowd that hardly seems to diminish as the afternoon wears away, with their sighs and tongue-clicks, reprimanding gazes when one tries to slip away for five minutes to eat something, long after lunch time should have been. And this not once, but every day, unchanging over weeks and months and years, although not many doctors stay that long in this hospital. It is unsurprising that many people we speak to say the same thing: “There is no care there, at our hospital.”

And so Nozukile continues:

NOZUKILE: I went to the private doctor, and he did a scan for the pains in my stomach, and he did not see anything. And I went to the scan repeatedly and he did not see anything.

³⁵ The direct interviewer was almost always Xaks, although sometimes with my participation and input. Where the term “interviewer” is used in the text, our collaborative efforts are implied. Where I considered it significant which of us was speaking, our names are used instead.

“This continued until I went to a specialist doctor, who did not see anything.

“The doctor would say he does not see anything wrong with me and he will not treat me for something he does not see.

“He could see that I am very ill but when he examines me, he says he does not see anything.”

I start to wonder, in the light of her piercing interpretation of “Panado, B-Co and Brufen”, what this failure to see had meant to her. I imagine the doctor, on each occasion, delivering this verdict in different ways. “I do not see anything wrong” - as a reassurance? “I do not see anything wrong” – as a negation of her experience, her fears? “I do not see anything wrong” – and you are wasting my time?

Again, she has captured the reductive, even myopic gaze of the healthcare worker, returning it with her own. While quiet in the encounter itself, she is nonetheless watching closely, with a gaze that is expectant, evaluative and insightful.

What I cannot understand is that in spite of this perceptiveness, she has accepted this formulaic and unhelpful response repeatedly.

INTERVIEWER: If someone would ask you whether you want these pills [again], when they have been given to you previously, what would you say?

NOZUKILE: I would take them even though they are not helping me.

INTERVIEWER: Why would you take them, are you hoping they will help you?

NOZUKILE: Having them is better than nothing. At least I am taking something for my illness.

She adds:

NOZUKILE: I just live in hope that maybe one day, I will get the one doctor that will know, and will help me with my problem.

To me, this apparent passivity is inexplicable when seen alongside the effort she expends for these encounters. My perception of the empowered patient is along the lines of a consumer, who says: “I have paid for this (if indirectly), and I will make sure that I get what I paid for.” But I can’t recall ever having seen a Xhosa patient respond in this way, and I’ve put it down to disempowerment, possibly intimidation due to the status of the professional, and perhaps an unquestioning belief that the doctor or nurse (or occupational therapist) “knows best”. The latter is hardly the case with this woman.

This is the first time I am hearing an account of this kind of encounter from the perspective of the person seeking care, and it takes me time to “hear” her. I cannot detect frustration or anger, and her words are understated and brief. In our first interview, I try to press her for a more personal response, and Xaks has to intervene: she is almost in tears. To my shame, I am too fixed on words to notice until he stops me. My ear is not yet calibrated to hear the silences and understatements with which the most serious things are communicated in this community.

Having before me her account of all she had gone through to seek help, I was convinced the illness was “real”. I saw the solution as a thorough work-up to identify the medical cause and thereby the correct treatment, and so I approached the clinic sister, who performed a more detailed clinical assessment, and then wrote a letter referring her to hospital. A few days later I dropped her at the hospital gates on my way into town. Her dawn arrival (never possible when using public transport

from the village), allowed her a place in the front of the queue, and she was seen by the doctor before lunch.

What happens next throws me completely. This is what I wrote about our next visit:

“Finally we went to see Nozukile, who was her smiling self, busy sewing. The doctor at the hospital saw her early - she was on the bus by eleven - and did a very thorough job, judging by her very neat and fairly extensive notes³⁶. From Nozukile’s description, we think it was [the young female doctor] whom we met today. She was very sweet to Nozukile, reading our letters, and doing a full examination³⁷. I’m not sure what she prescribed (she added two new drugs to the list, which I didn’t recognise), but she took a load of bloods (LFT’s, U&E, FBC³⁸, etc). And even though the doctor said she didn’t know what was wrong with her, since then Nozukile has been fine!! Who knows what to make of that - I wrote down a couple of the drugs, and I’m going to ask [a pharmacist friend] about them, but there’s always just the benefit of being taken seriously and reassured. She’s going back for blood results on the 28th May.” (Field notes, round 1)

Although delighted Nozukile had found help that satisfied her, to be honest, I was disappointed that a clear diagnosis hadn’t been part of the solution. Perhaps I still wanted an explanation that would prove all the previous health-care workers wrong, for dismissing her complaint as “not real” in their terms. At the same time, I don’t think I trusted a non-medical solution to be an enduring one. I still felt, however unconsciously, that “real” and “imaginary” were the categories available. “Just the benefit of being taken seriously”, balanced against the medical terminology for what, on a clinical level, had been done: the emphasis betrays my continued feeling that the “imaginary” was lesser.

We tried to understand, from Nozukile’s perspective, what it was that was different this time:

INTERVIEWER: Can you tell us what happened at the hospital?

NOZUKILE: The doctor checked me, and examined me using her stethoscope and she said she is not sure about what I have, she does not see anything. She even took some blood samples, and I will fetch the results on the 28th of May. These are the pills she gave me.

INTERVIEWER: Did she tell you exactly what the pills are for?

NOZUKILE: No she did not. She just wrote a prescription and then I fetched the pills from the dispensary, where they just gave me directions on how to use the pills.

³⁶ I am contrasting these with the more usual forms of record, as described above. For me, the careful notes reflected a taking of time and of care that was in contrast to the usual treatment Nozukile had received. Such detail and neatness is also often limited to young clinicians. More experienced healthcare workers may become both more efficient in identifying the salient information and tests for a particular patient, but also less attentive to detail, both in their assessments and in their note-taking.

³⁷ Both clinic workers and other participants noted that hospital doctors often did not read referral letters, and that their examinations were cursory. It strikes me on re-reading this statement how these two actions by the doctor were noted by me as “sweet”, marking them out as unusual in hospital practice, rather than completely routine.

³⁸ Liver function tests, urea & electrolytes, full blood count – common screening tests for a wide range of illnesses. Including these acronyms marks my “medical” lens at this point: I am still looking for a physical diagnosis as a solution.

It sounds the same: the doctor says she “does not see anything”, and no explanation is given³⁹. But the next thing Nozukile says is:

NOZUKILE: I am fine since coming from the doctor.

What made *this* “not seeing” different?

NOZUKILE: This time I was satisfied. I think the doctor I got did her best. I am fine ever since I saw her.

INTERVIEWER: What made you satisfied this time?

NOZUKILE: It is because I am fine now, after getting an injection, and taking pills. I am relieved now. Usually I would go to the doctor, and come back only to find that there is no difference, even from that very same day I was seeing a doctor. Now I sleep nicely, since I went to the doctor.

There are several things that puzzle me here. Firstly, my idea of the placebo effect of medication is a simplistic one: it does not matter what medication is given, as long as there is “something”. It does not explain why the medication administered on this occasion was effective, when “Panado, B-Co and Brufen” were not.

The second thing is that she also attributes her satisfaction to being “fine now”: a condition that she clearly expected to arise almost immediately from a proper consultation: “even from that very same day”. It is not clear whether this expectation is solely founded on the action of the medication (it is possible that she wasn’t aware of potential time lapses before treatment may show an effect), or whether she expects the consultation in itself to confer healing.

Finally, “I do not see anything wrong” had previously seemed to be the crux of an unsatisfying consultation. I had understood her to be contrasting this statement against her own obvious suffering, to demonstrate the doctor’s inadequacy, as well as a possible suspicion that he believed her complaint was “imaginary”. And yet at this encounter, the doctor reaches the same conclusion, with a completely different outcome. What was it that had changed so dramatically?

We return to this question in subsequent visits, still trying to understand what it was that made the difference. Sometimes, she seems to credit the medication alone:

NOZUKILE: Those tablets I was given by the doctor were the ones that were healing me, because after that time I was 100%, up until now. The name of that doctor was Dr S, and she was a woman. She was checking me, checking me, checking me, and I was undressing, and she was taking the blood. I was having something that was making me hungry, like something special. So now after I was using that medication, that thing, I’m normal like another person, hungry like another person. I was getting help because the doctor doesn’t give me the Brufen and Panado, she was giving me another medication. It was that medication that was helping me a lot.

But despite the statements that seem unequivocal (“it was that medication that was helping me”), there is more to this. She names the doctor, something I come to realise has significance in others’ stories as well. Xaks later says to me:

³⁹ Medical information is often seen as a means to ‘empower’ a patient, assuming that if she has an understanding of her illness (or at least, one similar to the healthcare worker’s), she will be more motivated to comply with treatment and other advice (also described as “taking responsibility for her own health”).

XAKS: Before you [a doctor] examine me, I want to know your name and your surname, so that whatever can happen, I can know who I was dealing with, know whether to go back to that doctor, if he was good. I can follow him to [another town] if he was transferred.

It's not only about identifying someone you can approach for help in future. He adds:

XAKS: And then if I see [that doctor] in Shoprite I can greet him with his name, and he is going to smile. Some of them tell themselves they are the best people in our lives – I won't greet that one. The good doctor is the one who is humble, willing to greet.

In contrast, in an interview with another participant, Mamthuli, we asked which social worker she had been to see. She replied:

MAMTHULI: Those children who are working [at the hospital], they are silly and cheeky, so I was getting tired of them. I didn't look at their names.

Not only does she see no practical purpose in remembering their names, because they have not helped her, she also seems to be denying them acknowledgement, perhaps since she feels they have treated her in the same way. Nozukile's mention of the doctor's name and gender gives the sense of acknowledging the doctor herself, and not only the medication. She did not provide these details about anyone else she had consulted, excepting the private doctor⁴⁰. She may also be naming Dr S here to "recommend"⁴¹ her to the group to whom she was speaking (a small focus group of some of our participants).

The second thing that was significant was this:

NOZUKILE: She was checking me, checking me, checking me, and I was undressing, and she was taking the blood.

She had returned to the point of physical assessment several times in our conversations:

NOZUKILE: My urine was tested and I was pricked on the finger for sugar diabetes, and they said I am fine... And I saw the doctor who did not even touch me and told me that I must go and breathe in a paper bag.

⁴⁰ Private GP's in this area are few, and they are known by name far more commonly than doctors at the hospital. This is largely a function of the nature of private practice, in contrast to the high turnover, staff rotations and shift-work of public service. In the former, one chooses a doctor whose reputation is known, whereas in the latter, there is little choice or predictability. The significance of naming one's hospital doctor is clearer when this is taken into account.

⁴¹ "Recommend" is the translation used locally for the term *ukuncoma*, otherwise translated as "to compliment". Xaks and I had a fascinating conversation about the difference between the two, when we had to differentiate between compliments and recommendations, with regards to hospital and clinic complaints boxes. Xaks had asked a hospital manager whom he was interviewing, about recommendations received via these boxes, and she responded by describing what I would call compliments. I would have read a significance into this that wasn't there, without Xaks' explanation. I felt "compliment" was a better translation of *ukuncoma*, but on further reflection, this is inadequate. For English-speakers, a compliment tends to be addressed to the person in question, whereas *ukuncoma* seems to be more of a public statement, a positive contribution to that person's standing or reputation. Given the emphasis here on one's social position or "dig" (dignity), *ukuncoma* is something weightier than to compliment. This explains the common translation to "recommendation" – but raises interesting questions about the use of these boxes by Xhosa-speaking people. It would be interesting to know if a Xhosa translation exists for the English understanding of "recommendation".

Xaks also remarked:

XAKS: She has confidence when the doctor puts the stethoscope on the chest, even though that one who was doing that didn't give her different medication.

He commented elsewhere that in this area, the stethoscope is "the most respected". We also conjectured that because of her palpitations, she reasoned that the doctor could not assess her problem without listening to her heart.

She confirmed the significance of this:

NOZUKILE: [I was helped] because of the care that I got from the doctor. Other doctors would not even examine me. They would ask me questions, write down and prescribe pills according to what I say, not according to what he spotted. But this one doctor prescribed according to her examination.

While I tried to tease out individual factors as causes for her satisfaction, over time I came to realise how the different elements of this encounter interwove to achieve this. The quality of relationship with the doctor was key: kindness, respect, a willingness to spend time and effort on her problem. While the physical examination seemed to be taken as evidence of clinical skill and good practice, perhaps the physical engagement with her body also contributed to Nozukile's experience of being listened to and cared for. In her description, there is a sense of collaboration, rather than simple submission to the doctor's actions:

NOZUKILE: She was checking me... and I was undressing.

They are engaged together in a shared task, in contrast to previous encounters, where her presentation of the problem was met with distancing and dismissal. Despite several of the elements in this encounter sounding the same as before (no clear diagnosis, prescription without explanation), the impact of the whole is entirely different. While the doctor is frank about being unable to identify the cause of the illness, Nozukile feels she "did her best", and this is satisfactory.

While we found no other instances of such strikingly successful engagement between our participants and healthcare workers, the essential elements recurred elsewhere. Kindness among nurses and doctors was commended wherever it was found, while a lack of caring was castigated:

FATHER (AY): The doctors, what they do, they put up a drip on you, and then they go. And when the nurses are coming to check, they ask among each other, what can we do, how can we help this one? [they don't talk directly to you]. They don't even give you a chair, they put the drip up while you are standing, and you must stand for two or three hours.

Caring was not only a manner of interacting, but also real engagement with the concerns of the person seeking healthcare. Mamthuli was the mother of a young man with cerebral palsy. During the first ten years of her son's life, she had travelled the length of the province seeking help for him – including making monthly three-day round-trips to the city for physiotherapy. In spite of her efforts, she found little that made any difference, and eventually gave up trying. When we asked her if any of her healthcare encounters had been positive, she commended the orthopaedic hospital, where surgery was done on her son's legs:

MAMTHULI: I think at [that hospital], I was treated so well and the treatment was super. The nurses were so kind.

INTERVIEWER: You said the operation was not successful, but you still think the place was good. What made it so?

MAMTHULI: In all the places I went to, they were the only ones who thought about performing an operation to make him walk...What I liked is their will to help, even though it did not help at the end.

By contrast:

INTERVIEWER: At physiotherapy, did they try to help him walk?

MAMTHULI: No, they just stretched him.

INTERVIEWER: So you do not feel the stretching was helpful?

MAMTHULI: I did not see any help in it.

The two interventions were equally unsuccessful, and yet her interpretations of the two experiences were totally different. She too was satisfied by the evidence that the surgical team had done their best, not only because she was treated with kindness, but because they seemed to be working for the same goal as she was. Given that physical cure was often impossible for our participants, no matter what was tried, this was a critical finding.

Through further conversations, we were able to build up a picture of what constituted good care for our participants. Gogo told this story:

GOGO: So if the nurse wants to inject me, and I have boils, I can say no, don't inject me this side, I have boils... And then the nurse can say, no, you know nothing, it's me who knows. Then the nurse can inject on the boil side, and then it can become swollen, and become a big sore... and when you go back to the one who was injecting you, it is not going to be nice. She was feeling ashamed, the one that was injecting, when you show, this is the thing you were doing.

Participants clearly valued the role they had to play in the healthcare encounter:

MOTHER (NC): You are going to help each other, patient and nurse, because you are asking a question, and the other is answering, so you are helping each other, both of you.

Gogo summed it up:

GOGO: Between the two of you, you know how to treat well.

While it was clear that individual healthcare workers made different decisions about how they engaged with people seeking their help, I had also reflected on how difficult working conditions impacted on their behaviour. It struck me how Nozukile's encounter with Dr S differed sharply with previous visits in terms of time and context. Because of her early arrival, everyone concerned was still fresh, and the atmosphere of desperation that blanketed the waiting room in the afternoons was not yet present. This may have influenced Dr S's willingness to carry out a thorough assessment, and the energy she had to engage. Nozukile herself also entered the encounter in a different state to previous visits. This time, she was there not because the suffering had become too intense, but because of our interventions to get her properly assessed. She was not in crisis, either physically or emotionally, and she had not spent hours on expensive and extremely uncomfortable transport to get there.

The corollary of this is that the usual conditions under which healthcare workers and seekers engage, are significant in shaping how these encounters play out.

I attacked this situation with a determination first to fix the problem itself, and then to understand exactly how it had been solved. In spite of being there as a researcher, not a clinician, I struggled in all of our encounters to resist the compulsion to solve things, both practically and intellectually. This orientation to action was exactly what made it so hard for me to understand how Nozukile could sit quietly and accept poor treatment. My difficulty “hearing” her underlined this: even as a qualitative researcher, I was taught to look for statements, for the quote which would capture what she felt and thought. I took her words and pulled them apart, trying to match them to deductions and explanations. It only occurred to me much later that my participants didn’t take words anywhere near as seriously as I did.

Nozukile’s story revealed some core elements in the engagement between our participants and healthcare workers that we found repeated in various ways across the different stories. Phindile, a young man with a mental illness, had a story that shed further light on these dynamics. While Nozukile’s illness was dismissed as “not real”, his was a condition recognised in law and policy, with standard procedures for its treatment. However, the tensions and contradictions in the system and in the broader context prevented these procedures from meeting their mark, with frightening consequences for the young man, his family and the community.

4.1.2. Phindile: Defaulters and grant-eaters

Basing myself in the village for some of the fieldwork, I had the opportunity to observe how our participants’ health needs arose and played out in the community where they lived. My hostess, the elderly but still active chief of the area, was a soft-hearted woman, who offered me the stories of struggling households, particularly those of people with disabilities, and asked for my help. Phindile was one of these.

We are sitting in the kitchen one morning, watching the chickens pecking at the earth floor, in the rays of early sunlight that slant through the door. Someone approaches from the yard, and she leans forward, whispering conspiratorially: “Here he is!” He appears in the doorway, a young man with dull, darkened skin, matted hair, loose hands and the bare splayed toes of one who seldom wears shoes. His clothes are colourless with dirt, breathing out the thick, musty smell of long unwashed skin.

She greets him softly, offers him food. He grunts a yes, without greeting. I go to the stove and spoon *pap* and soup⁴² onto a plate. He is seated on the chair by the door when I turn back and place it in his hands. Now his body is animated, his fingers around the spoon, shovelling the food into his mouth. Gogo and I sit hushed and watch him. He clears the plate, wipes his mouth on his sleeve and places it on the floor. Then he is on his feet and out of the door again, gone without a word.

After he has left, Gogo tells me:

GOGO: He is always coming here for food. His family, they don’t care for him. He has no jacket, he is sleeping outside in the cold. They are just eating the grant, even though now there is no grant for him.

⁴² *Pap* is maize porridge, a local staple, and “soup” is a reconstituted soya mince mix, often eaten as a sauce with *pap*.

Phindile has a mental illness, diagnosed a number of years previously, but seems no longer to be taking treatment. His grant has been stopped, for reasons unknown, but an application for renewal will not be successful unless he is compliant with treatment⁴³. We discuss how to get help from the social workers, how to get him a grant that is protected from family exploitation. I ask my mother to find him a second-hand jacket in Cape Town. I am still more than willing to step into the role of helper, to accept the invitation to solve.

The problem as Gogo has presented it seems a common one. In early conversations with the clinic staff, we ask about the challenges they face with people with disabilities in the community. They tell us this:

CLINIC NURSE: The families, they are neglecting [the people with disabilities]. They care for them one day in the month, when they take them to pension point⁴⁴. Then you see, these people are now clean, they are wearing shoes, nice clothes. After that the family just leave them in the house, not washing them, not changing their clothes, not taking them to the clinic for treatment. The families are just eating the grant.

A few days after my first encounter with Phindile, we visit the young man's home, Xaks and I with the community health worker, known here as a *nomakhaya*⁴⁵. Phindile is out, somewhere in the community. We speak with his brother.

BROTHER PD He was born in 1981. He has always had this problem. Our parents were deceased in 2004, the problem became worse after that. One day he came into the house and kicked over the pot from the stove, when my wife was cooking food. After that he start to go out all the time, come home late and leave very early in the morning. We took him to the hospital, he got better with the pills. While he was taking the pills, he becomes fine, comes [into the house] every day, jokes with us and he talks sense, it becomes nice to be around him.

INTERVIEWER: Does he need help to take the pills?

BROTHER PD: I would remind him that he must take them after a meal. And when it is time to go to the clinic, I tell him before he goes to bed that we are going to the clinic the next morning. Then I prepare things for him in the morning and we go. And things go smooth even at the clinic, he does not give me troubles.

INTERVIEWER: But now he is not taking the pills anymore.

⁴³ Grant applications must be supported by a medical report, and the standard assessment form includes a question about whether, in the doctor's opinion, treatment has been optimised. This is sometimes misunderstood as refusal by healthcare workers to award a grant unless a patient is compliant, but technically this is not the case.

⁴⁴ Social grants, including old age pensions, child support grants, and disability grants, are paid out in cash once a month at designated pay points, usually local trading stores. The money must be collected by the beneficiary in person, hence the monthly outing described here. Such payments constitute most households' main income, and disability grants are often used to meet the needs of the whole family, not primarily those of the disabled person.

⁴⁵ Community health workers have historically been volunteers from the location, based at the clinic under the nursing staff, and sent out to visit people in their homes for health support. They also perform duties at the clinic itself, including weighing patients, counselling people, and managing the queues in the waiting area. They have variable training (here, little or none), and may be paid a small stipend for their work. Their role and situation is explored more fully below.

BROTHER PD: No. The problem is he is not available. He is leaving very early in the morning, before we are awake, and coming very late in the night. Sometimes he is not coming home for two, three days, and we don't know where he is sleeping.

INTERVIEWER: What do you think about this?

BROTHER PD: I am not happy at all that he is not taking his treatment and he does not want to eat. What I do if he is in the house in the evening, I lock his room⁴⁶ from the outside and since his window has got burglar bars, he cannot jump out and then in the morning I give him water to wash and prepare him to go and get treatment... That is when I get him, otherwise very early in the morning he would leave.

INTERVIEWER: But you haven't been able to catch him like this to take him to the clinic.

BROTHER PD: No.

INTERVIEWER: Do you have any questions for us?

BROTHER PD: Is there any way that he can get the grant, even though he is not taking his treatment?

Ah, we think. It really is just the grant that the family are concerned about, not Phindile himself. Later, we reflect on this:

XAKS: His brother said, "I'm waiting until he comes" – not that he goes to look for him, just checks in the room, and he says, "He comes most of the time while I am sleeping". If he wants to take care of [Phindile], he can look at the time [in the night] and go and check if he is there yet. Also, the sister-in-law was starting to smile when we were talking about getting the grant again, and then she started to talk.

I write in my fieldnotes:

"Between what I understood and what Xaks translated, I didn't get a good sense of what Phindile's brother was feeling about the situation. I did feel a lot of heaviness at the end of the interview, though, between him and his wife, that this thing is a burden to them. It's hard to gauge how much they really care about Phindile, and to what extent they have given up - I don't know. It's so easy to judge from the outside... I guess looking for Phindile also takes away from the business of survival – [the brother] was taking the cows to the mountain when we found him, and he spoke about doing piece jobs. I think I heard his wife tell the ward nurse she was working on the road. And they have children." (Field notes, round 1)

Having begun with Gogo's version of the story, my main question is about whether the family are doing their best for Phindile. Do they *really* care?

We have just left Phindile's house after that conversation, and begun our next interview in a neighbouring house, when the sister-in-law arrives. Phindile has come home: can we help? We put him in the car and drive him, with the sister-in-law, to the clinic. It is late in the morning, the clinic is packed, but when the nurse sees us with Phindile, she agrees to see us ahead of the queue. In the corridor off the waiting area, she pores over a drug register, and gives the sister-in-law a hard time about his medication, berating her for not making sure he takes it. The sister tries to defend the family,

⁴⁶ Phindile's room was a free-standing building within the family homestead.

but is overridden. The nurse counts the months since his last script: more than three. According to policy, he cannot be given his medicine here, he must go to the hospital in town, to see the doctor.

A few days later, I ask the nurse about her dealings with this family.

CLINIC NURSE: We used to see Phindile, he was brought in by the brother when he came from hospital. His brother was promising he is going to look after him and make sure he takes the treatment. Then after two months, he didn't come to the clinic, after two months, we saw Phindile walking alone in the street, he was very dirty, not like before. We noticed that he is not taking treatment any more. We tried, Mrs Magida and I, to get him to come to the clinic. He's not talking much, he is quiet, he just say ok. We tried to send a message to the household that he must come to the clinic, but he didn't come.

"His brother promised he was going to take care. But I don't know what went wrong, really."

To both the community members and to the healthcare workers, the family are the focus in this story. They are the ones who are responsible: for taking care of Phindile and making sure he gets his medication, and also for his illness when this fails. The existence of the disability grant has been woven into the tale to create another kind of label or formula: the grant-eating family who allow their relative to sleep in the cold and beg at neighbours' homes for food.

The nurse writes a brief referral note in Phindile's card and returns to her queue. It is late morning, the day is hot outside, and the patients fan themselves with their clinic books. The buzz in the waiting area is impatient, they have been here since early in the morning, but they will wait a while yet.

The transport to town left hours ago. The lumbering government bus at 5am, the crammed *guru-guru's* with their groaning canopies – all will return later in the afternoon, but for now the roads outside are quiet. I confer with Xaks. If we leave things to take their own course, the family will have to wait until they can both catch Phindile at home in the early morning, and get him onto the transport to town, in order for him to get to the hospital. What they will do if he resists or becomes violent, I don't know. We agree the best is to take him to hospital now, ourselves.

I query the process with the nurse at our later interview. Why could he not get treatment at the clinic?

CLINIC NURSE: No, if the client has not taken for three months, he is a defaulter, he must be reviewed by the doctor. Maybe the illness is complicated, and he must be seen by the doctor.

KATE: And is it possible when that happens, for the family to take the patient? We had a problem because they had no money to go. Is it usually a problem?

CLINIC NURSE: They always complain about the money, but the ambulance will not come for the psychiatric client, they say it is a police case.

I hear later that the police, in turn, will only involve themselves if there has been a crime: an assault, a rape. Someone who is merely unpredictable, or potentially violent – the family (and the other passengers) must take their chances on public transport.

Over an hour later, we arrive at the hospital, navigate security, the clerks, and find our way to the waiting area and the queue. It is almost midday, the place is heaving, and I send Xaks to talk his way to the front of the queue. We can't risk being sent home without Phindile being seen⁴⁷.

We wait. We read the posters on the walls, about "Rights of People with Psychiatric Disabilities", and "Cancer Can Kill". I watch a school child sounding out a Xhosa notice with his forefinger. Xaks takes down the words from "The Tree of Mental Illness" (alienation, alcoholism, resentment, isolation). I go to look at the TV, directed into the part of the waiting area where there are no people, the sound turned off. Two women are watching it and trying to work out what is going on. Nurses move up and down unhurriedly, punctuating their activities with heavy sighs. Forms are filled in, masks go onto faces going into consulting rooms, bloods and results are ferried to and fro. A child screeches, is comforted on his granny's back, and is playing a while later. A consulting-room door swings open and we get up to enter, only to be waved away by a doctor going on lunch. I buy food for us - bread and russians⁴⁸ for the other three, and scones for me, from the stalls at the gate. They must do a roaring trade, I think. Little as anyone here can afford to spend, sick people must eat. Phindile finishes his own food, and the end of Xaks', and half an *igwinya*⁴⁹ another woman gives him. She is morbidly obese and dozes while we wait. I offer her a scone but she says thanks, she is full. The contrast between the bright posters with their human rights messages, and the chaotic scene around us, is deeply ironic.

Eventually, the doctor returns from lunch, and we are seen. A black man, probably in his late thirties, the doctor is brusque. He asks the history, the sister cannot match his efficiency in getting the story out. He becomes impatient, turns to Xaks, who gives a more schooled account. He has spent enough time around health professionals to know how to tell this story. The doctor turns to Phindile, asks him a few questions. Phindile responds softly: yes, he knows where he is: at the hospital. No, he doesn't hear voices. He wanders up and down "for fun". Then the doctor waves him to the bed behind the curtains and tells him to strip, and asks us to wait outside.

Xaks and I both note how the sister-in-law seems lost at the hospital. She doesn't know where to go, and she struggles to speak with the doctor. We ask her later:

XAKS: If you remember that time at the hospital, you were someone, when the doctor was asking about Phindile, how is he at home, you were just closing your mouth, and when you talk, you talk slowly, softly – not loudly so that doctor can hear and understand you. But it is very important to talk so that doctor can understand his behaviour at home.

SISTER-IN-LAW PD: That time I was quiet at the hospital, it was because I was waiting on the doctor. When he was asking Phindile why he is not taking the treatment. And when he asked me I was going to say, it's because he is running around in the location. But the doctor was asking Phindile and not me.

At the time, it makes me think about the skills required to navigate the hospital system. Knowing where to go, whom to speak to, what papers, stamps, measurements are required. Then knowing what to tell the doctor: there is no time for subtlety, uncertainty or detail. I worry that she is intimidated by the doctor, and that this prevents her from making herself heard. Thinking back now, I wonder more about what the doctor was doing. Would he have behaved differently if she was more

⁴⁷ There is a tension here between observing and intervening. Part of me felt I should let it run its own course, but having committed to helping, I wasn't prepared to let it fail. I also couldn't face the thought, physically or mentally, of sitting through the afternoon and then being required to come back again the next day.

⁴⁸ Russian sausages

⁴⁹ Deep-fried dough ball, "fat cake"

confident, or did his response have something to do with her being an obviously rural (and therefore less educated) woman, or related to someone with a mental illness?

We wait some more. It is almost four o'clock by the time bloods have been taken, medication administered, forms filled in. Eventually, we catch up with Phindile and his sister-in-law, and learn from the doctor's notes that he is being admitted for observation. They don't seem to know this. Xaks is sent to the clerks with a stack of papers, and then we find our way together to the male medical ward, where the sister on duty fills out more forms. Xaks makes another trip back to the clerks: a stamp is missing on one of the pages.

The ward nurse tells the sister-in-law to bring Phindile clean clothes, because his are dirty. Already simmering from the interminable process, I can't help muttering to Xaks, "How the hell is she supposed to do that?" The nurse also turns to Xaks. "*Uthini, Zulu?*⁵⁰" she asks, as if she does not understand me. I answer, in English. I am worried about how she will bring the clothes. She looks me in the eye: why? I say, because she lives far and has no money.

The nurse is vindicated by the sister agreeing to send clean clothes to town with someone else. Of course.

What the nurse says to me later sheds some light on this interchange:

WARD NURSE: We usually get challenges. Firstly, the patient is usually [just left here] by the relatives, so after the 72 hours, you don't get the family members to come and fetch the patient.

DOCTOR: Also some of the challenges we face, the relative brings a patient, and never comes to visit them, ever... We are here to help, but ... I have to see 35 patients, I can't sit with them, you know, one on one, and want to hear what their concerns are... When a relative is there to lend an ear, it's much better. Now if the relative just drops the patient and leaves, with no trace, with no number, no anything, now we have to play detective. There's a [psychiatric] patient who stayed here for more than a week, with no relative coming, we had to play detective until the guy left.

To them too, the families are the ones who are responsible, even more so given the lack of capacity of the hospital staff. Again, I don't understand: if a rural family must make two trips to the hospital in a week, before and after the 72-hour observation, how could they possibly be expected to visit in between? Finance aside, I'm thinking about time. For Phindile's family, I can only imagine those three days would be precious, a chance to attend to the household, perhaps do piece jobs, without needing to worry about their brother.

But clearly I was wrong to raise this with the nurse as I did. What right does some unexpected white person, some outsider, have to interfere with their exercise of authority? How dare I imply some superior understanding of her patients? The nurse turned language on me: pretending not to understand me, she mocked my assumption that she doesn't understand where this family is coming from. She is also Xhosa. At the same time, she was effectively putting me aside: she is speaking to Xaks – "*Zulu*," that term of relation - not to me. This was not the only time I trampled, ill-advisedly, on professional territory. But while I recognised the particular threat I might pose, as an outsider and perceived critic, I also knew that as a white person, I was often afforded a respect and indulgence

⁵⁰ "What did she say, brother?" The term *Zulu* is used specifically in this area, where the local population is descended mainly from a group of amaZulu who fled the aggressive empire-building reign of King Shaka, further north, in the early nineteenth century. The residents of Mt Frere area, known as the amaBhaca, speak a dialect of isiXhosa which retains many isiZulu terms. They habitually call one another *Zulu*, denoting respect for a kinsman.

which my participants could not expect. If my questioning of staff actions was met with hostility, how could the healthcare users themselves possibly do the same?

So Phindile is admitted, under the Mental Health Act provision for involuntary committal and assessment of a patient who is a danger to others and/or himself. I am not hopeful that this period will be enough to stabilise him on his medication, but before he can be referred on to a “designated” (psychiatric) hospital, this has to happen. At least now he is back in the system, I think.

I hear nothing for a few days. On the Friday of that week, Phindile’s brother takes the transport money I give them, and goes on the taxi to bring Phindile home. His 72 hours are up, and he is discharged.

The ward sister later explains:

WARD NURSE: We have got the policy that says the patient must be admitted for 72 hours assessment, and after 72 hours, must be discharged, unless the patient after that 72 hours is still aggressive, then must be transferred straight to a designated hospital, so that is what we usually do... If the patient needs to be transferred, then the doctor usually arranges with the doctor from the psychiatric institution, so that the patient will be admitted there. The challenges that we get at times, that there are no beds there, so they will say you can wait, give this and this [medication], till there are beds. Or they say you can send the patient, but the challenges that we get are the challenges of transport, because we have got a transport problem...

KATE: What was your assessment of Phindile during his observation period? I know you have many patients and it was a few days ago...

DOCTOR: He was very cooperative. And we didn’t see any violent behaviour during his stay here. So that’s why, after the 72-hour assessment, then we decided, he was fine to go to the community, because he was not a danger to himself or anyone else.

Of course there wasn’t any violent behaviour, I think. You drugged him to the eyeballs. But then this:

WARD NURSE: It’s rather difficult, especially because the environment [at the district hospital] is not conducive for the psychiatric patients, because there are no burglar [bars], so at times, when a patient likes, he absconds... And at times, security guards refuse to come and assist us... And then you find that you are females, so you cannot do anything to these psychiatric patients. And at times the patient becomes aggressive, even to others, there are those that are ill⁵¹. So that’s why we need to guide them, always, but that is not possible because we are nursing about 31 patients, so when you are in room 1, you don’t know what is happening in room 7. And we are only four [nurses on the ward]... oh, they are so destructive, it’s not conducive...

The legal imperative of a 72-hour observation must be observed, but without the essential resources. What results is an adapted procedure that goes through the motions, without achieving the intent. The healthcare workers have no apparent alternative.

And so Phindile returns home. Has a meal, takes one dose of his medication, and then disappears again.

⁵¹ She is referring to other patients admitted for physical illness, who share the ward with patients who are mentally ill. Her concern was distressingly illustrated in January 2015, when an elderly woman was raped in the ward by a mentally ill male patient, during the night.

The clinic nurse watches this from Kwabisi. It has happened before.

CLINIC NURSE: Because they are supposed to keep them for 72 hours for assessment, then Phindile is quiet, the nurses and doctors are seeing this one is not violent, and they say no man, this man must go home. But they don't see that he is not well...

I see him intermittently, in the next few weeks, walking in the road, or making brief appearances in Gogo's kitchen for food. Shortly after his discharge from hospital, I go to interview the ward sister, and the doctor who saw him while he was admitted. I want to understand what happened there, why they sent him home.

DOCTOR: Oh, *heeeh*....Did this patient say it was *dagga*⁵²-related, did he actually admit to that? I can't remember, some of them do admit, some don't, we have to hear from the relatives...

WARD NURSE: He admitted that he was taking *dagga*.

DOCTOR: Ah. You see, if he stops smoking, then there's a chance for him because he's normal...and he can go find a job and make a better life for himself. I always tell them that the onus is on you, it's your life... most of them are aware that, I'm crazy because of the *dagga*. OK, fine. If you know that, then you can leave the *dagga* and you will lead a normal life. It won't be a problem.

We know Phindile is smoking *dagga*. The young boys, fifteen to sixteen-year-olds, know that his brother gives him money, and they easily persuade him to let them buy for him, and for themselves. While it is undoubtedly unhelpful for his mental state, it also adds another layer of complication:

SISTER-IN-LAW PD: When the clinic sister is writing a referral letter, the doctors are not reading the letter, they just ask Phindile, when did you last smoke *dagga*, and they rely on that – they don't even look at the letter.

The doctor writes in the card: "substance-induced psychosis". This means something different to other diagnoses: this man is responsible for his illness. There is a simple solution, and it is in his hands. The words remain on the card that Phindile will carry into the clinic, the hospital, next time. Like Nozukile's prescription for "Panado, B-Co and Brufen", they are the kind of phrase every subsequent clinician will feel obliged to repeat.

I cannot be sure the drug isn't the sole reason for his illness, but the healthcare team don't seem to have considered the alternatives. Of course he is unlikely to get better while smoking, but after delivering a few lectures on the dangers of *dagga* myself, it occurs to me that he is self-medicating⁵³. And that, as a young man in this community, there is really nothing else for him to do⁵⁴.

⁵² Marijuana, commonly grown and used in the area. The drug is known to trigger psychosis in many users, some of whom develop life-long psychiatric illness as a result.

⁵³ The relationship between substance abuse and mental illness is complex, and "dual diagnosis" is a term sometimes used to refer to someone with an underlying illness, such as schizophrenia, who is also using drugs or alcohol, as is often the case. When the prescribed medication is failing to address distressing symptoms (mood, anxiety, hallucinations), *dagga* may seem to offer relief. The assumption of the doctor here that Phindile was "normal" without the *dagga*, was not the only indication that psychiatric knowledge at this facility was limited. See later discussion of violence and dirt as proxies for illness.

⁵⁴ Given the lack of employment opportunities, young men who have left school have very few options for meaningful roles in this community. Those who are motivated to work generally leave for the cities, while

We have followed the protocol, intervening with our outsider influence when we thought necessary. We have done all we can, and it has changed nothing. We go to Phindile's home, to find out how things are.

BROTHER PD: I last saw him when we were coming from the [hospital], that was all. He did not take yesterday's medicine. We cook and he does not eat - seemingly he eats in the place where he goes. His situation is on and off.

The brother is drunk, although it is ten in the morning. He has tears in his eyes.

BROTHER PD: As young as I am now, I sometimes wish I just die, because of this difficult situation.

He is drinking a lot. Xaks says it is because of Phindile. He asks the brother, but he doesn't give a reason. "There is no ceremony⁵⁵ that is happening," Xaks says. "He just goes to drink at the *shebeen*⁵⁶." Xaks feels the wife needs to step in, to help Phindile. The brother is unreliable, because he is drinking. She is a woman, it is for her to "mould the house". We ask the *nomakhaya* for her opinion: what could be done?

NOMAKHAYA 1: I asked his sister-in-law that they must show him some love, things like serving him food on a tray [in his room], so that he can feel their love as a family. She told me that the problem is Phindile would wake up very early in the morning and leave, even at the time he was taking treatment.

What about the *nomakhaya*? What is she doing when she visits? She is sent by the clinic, to the families of those who are defaulting on their medication.

NOMAKHAYA 1: I check his card, and see whether his family is taking good care of him and I advise, because the person needs love, so that the community can do its part. We did not have any training about this thing.

She also tells them to take him to the clinic.

Everyone is pointing to the family, it seems: it is their responsibility to help him get well, and specifically to make sure he takes his medication.

CLINIC NURSE: We don't see the client by himself, we want that he must be accompanied by the relative, because he does not know, he is mentally disabled, maybe he will not know that this [pill] must be taken at night, this one in the day, so he must be accompanied by a relative, who is going to make sure he is taking the treatment at a regular time... The family can make sure he is taking the treatment, making sure that he is swallowing the treatment, not keeping in the mouth and spitting.

those who remain behind might help to look after family livestock and property, but seem to spend much of their time in the shebeens, or hanging around the location with their friends. By contrast, young women would be working hard in the households of their parents, or as *makhoti*'s (new wives) in those of their parents-in-law. Because of the cost of *lobola* (customary bride-price), young men cannot afford to marry unless their families are wealthy, or until they have built up substantial capital.

⁵⁵ Many Xhosa ceremonies require traditional beer to be brewed, and are occasions for men to drink together in a socially acceptable manner.

⁵⁶ Liquor shop, often unlicensed, where men gather to drink and socialise. In these areas, where few are employed, shebeens may be busy from morning until late, on any day of the week.

But on a purely practical level, can they actually do this?

SISTER-IN-LAW PD: It's quite difficult to help someone like Phindile. Because sometimes I give the tablets, and sometimes Phindile's own sister gives the tablets. And he is running away. Sometimes Phindile is running to another brother's house, because at home we are trying to give him the treatment. If you try to help him, he is leaving you and going to the one who is not giving the tablets.

If the person isn't willing to swallow the pills, what force can you (may you?) exert, to fulfil this responsibility for your relative? A rumour emerges: Xaks suspects that the brother beats Phindile to get him to do what he wants. His suspicion is based on how the brother referred to Phindile as "*lo, lo*" - "that one" - a term of disrespect. Also the fact that Phindile usually listens to his brother, although not to anyone else. We ask the *nomakhaya*, when we see her.

XAKS: Do you think Phindile's brother is forcing and beating him to go to the clinic?

NOMAKHAYA 1: No, I do not think so. But I heard that lately it is Phindile who is fighting his brother, because he does not want to go to the clinic. And he even beat and kicked his aunt when she told him to go to the clinic. I also heard that he asked for sex from one woman in the neighbourhood. And now I feared, he is becoming dangerous... I'm scared maybe he can rape children now...

(she pauses)

I even suggested that maybe the family ask the young men to tie Phindile up and take him to the clinic - because I was feeling for him...

And just like that, force is not abuse, it is help, compassion. On the other side of the world, in a European conference room, I speak with a Dutch worker from a disability NGO. "I hear that in Africa, people are still chaining up their family members who have a mental illness," he says. "How can it still be like that, even today?" I don't know what to say.

When we speak to the brother, he expresses the dilemma:

BROTHER PD: I used to put the *waskom*⁵⁷ [out] for him, and tell him to go, and he would go and wash. But it's getting more difficult now. Now I say, "I will call the police and tell them, this guy is not washing, take him away!" and Phindile responds to that, because he is afraid of the police... I understand [this is not the right way], but I was threatening him just to change the situation, because there is no other way.

The family are only too aware of the judgments, on all sides.

SISTER-IN-LAW PD: We have to talk truth. I don't want to go again to the hospital, because the doctor I met there last time was so rough, so I don't want to go back again to him...I can go back there when I hear that that doctor is not there anymore.

⁵⁷ Washbasin

SISTER-IN-LAW PD2⁵⁸: (*nodding sympathetically*) Maybe he is rough because Phindile is taking three months not eating treatment, so maybe he thinks the family don't care. When we were arriving at the hospital, the doctor was asking, why are you not taking care of Phindile? Then my sister was saying, we are taking care, but he was not staying in the home, he was wandering in the community. We were trying and trying. We bought soap and towels so that he can wash himself, but he doesn't want to wash himself.

"Care", brought down to its practical tasks, is making sure he is taking his tablets, but it is also making sure he is clean. Hygiene seems to become an easily observable proxy for care, and the family knows this. But then the sister adds this:

SISTER-IN-LAW PD2: And as the *makhoti's* we are supposed to intervene and wash Phindile. But with our customs, we can't wash the brother of our husbands⁵⁹.

At first, I am surprised that the Xhosa doctors and nurses would not think of this. Perhaps it is a very specific local custom, or one that has fallen out of use among more educated people. But then I wonder whether they have considered at all the practicalities of the care they expect from the family of someone with a mental illness.

I return to the issue of washing, realising how it recurs in the accounts we hear. His brother tells us, when we first meet:

BROTHER PD: When he is inside his house, I lock it from the outside, and since his window has got a burglar-proof, he cannot jump out. Then in the morning I give him water to wash and prepare him to go and get treatment.

On the day of our hospital visit, our opportunistic departure had given the family no time to prepare Phindile. I remember the exchange with the ward sister about Phindile's dirty clothes. The sister-in-law was not only subdued in the face of the ward sister's authority, she was ashamed. But there is a contradiction here. Dirt also means illness. Earlier the same day, the clinic nurse observed:

CLINIC NURSE: My assessment was, he is defaulting from treatment. When he came back from [an admission at the district hospital], he was very neat, but after he defaulted for three months he was very dirty, as if he is not even sleeping in the [house]. He is very clean when he is taking treatment.

So if you take your family member to see the doctor, you make sure he is clean, otherwise you are blamed for not caring for him, and his illness becomes your fault. But in the cursory examinations we have both observed and heard described, someone who is clean and well-dressed may also assumed to be well.

In the same way, the hospital staff reduced his assessment on the ward to the question of whether or not he was violent. Aside from the paradox of his sedation during the 72-hour period, it was clear that

⁵⁸ The second *makhoti* in the household, the wife of another of Phindile's brothers. She was only present at our last interview, but provided very useful insights.

⁵⁹ The behaviour of the *makhoti* is strictly regulated, and includes many taboos, particularly regarding other males in the household. For example, a *makhoti* may not directly address her father-in-law, nor use his name, or any word that sounds like his name. She also may not pass by the entrance to the *kraal*, the cattle enclosure, which is traditionally only entered by the men.

their chief concern was that he not be a danger to himself or others. This was echoed by the clinic staff. While I understood their overriding concern with safety, it was disturbing that they expected nothing more from someone with a mental illness, than not to be disruptive. Would this have been different had he been the head of a household, a breadwinner, or a mother with a family to care for? As a young man with nothing to do but smoke dagga, perhaps his contribution wasn't missed. If he was clean, and he was quiet, apparently that was enough.

At the time, I want to blame the healthcare workers for not helping, and I'd like to pin the problem on their distance from the day-to-day life of the family. They haven't seen the room where Phindile occasionally sleeps: a mess of stained blankets, collected rubbish, and faeces. I decide things would be better if the family members just told the doctor what it was like. Recalling the sister-in-law's reticence on our day at the hospital, I am convinced this is something that can be changed, something that can help. My theory lasts about two minutes.

SISTER-IN-LAW PD: But when you explain to the doctor [what Phindile is doing at home], the doctor says that this thing he is doing is because he is using *dagga*. Those things make me to be fed up... When I was trying to answer the doctor, he was saying to me, please close your mouth, I am asking Phindile not you. After that, the doctor didn't ask me anything. The only thing he was saying was that they are admitting him, because there is a small thing⁶⁰ that is making him sick.

Two things seem to be happening here. The family is actively silenced, which startles me: not only had the clinic nurse mentioned the importance of relatives at clinic visits, but I know that the outpatient service at the nearest psychiatric facility will not see a patient who comes alone.

The second thing is that Phindile's *dagga* use, on which the illness is blamed, is used to discount the seriousness of his condition. As the ward doctor says to us:

DOCTOR: You see, if he stops smoking, then there's a chance for him because he's normal...and he can go find a job and make a better life for himself... If you know that [the *dagga* is making you crazy], then you can leave the *dagga* and you will lead a normal life. It won't be a problem.

And so the system, and the healthcare workers, are absolved of responsibility.

As with Nozukile's story, I assumed that the solution was more "empowered" behaviour from the people seeking healthcare. I reckoned without the reactions from healthcare workers to anything like this, not only the sister's experience with the doctor, but also my own with the ward nurse. At the heart of my struggle with this whole interaction, was the expectation that the healthcare workers were as hell-bent on solutions as I was, as immersed in the complexities of the situation. It was not that they necessarily didn't care, they were simply trying to deal with the demands of the service. But there were limits to their position, as to the protocols which guided their actions.

What seemed to happen as a result, was a continual shunting of this troublesome family, from one space to the next. The *nomakhaya* sent them to the clinic, the clinic to the hospital. Neither seemed to consider the logistical difficulties involved, it was not their responsibility. The ambulance would not come for a mentally ill patient, the police would not come unless there had been a crime: the family

⁶⁰ The "small thing" is dagga use

must take responsibility for transport. At the hospital, the outpatient doctor admits him to the ward for “assessment”; the ward staff contain him with drugs until the 72 hours are up and he can be sent home. The family must take responsibility for making sure he takes his medication. Each player falls back on official protocol, creating a “procedural loop” that may be repeated indefinitely.

Within the family itself, the same story of blame is playing out. The sister-in-law tells us:

SISTER-IN-LAW PD: It’s difficult. In the house there is an auntie that we cannot decide without her, because she is older in the family⁶¹. So one time the brother was saying what if we can take Phindile to [the psychiatric hospital]. And she didn’t like that – it seemed to her like we want to throw him away....The auntie feels we are dumping him, instead of taking him to the people who have traditional herbs⁶². And she is blaming our brother that is working in Johannesburg, saying he doesn’t want to use his money to take Phindile to the *sangoma*⁶³.

Xaks comments to me:

X: In English, they say it, *igazi liyajhiya ngamanzi*: “blood is thicker than water”. Because this one is only the *makhoti*, the bride of the family, but she [auntie] is the blood of the family.

He himself suspects the *makhoti* would like to get rid of Phindile. She once said to him, “I am here in this house to marry”. Translation: this is not my family, I didn’t ask for this problem. He replied, “No, you are the woman here. It is for you to mould the house”. He too has chosen someone to blame. But it is clear in our conversations that she is aware that the burden is on her. She listens to the advice all around her, but then states, with quiet determination: “I will see what I am going to do”. The decision, in the end, is hers.

In a last bid for a solution, I urge the *makhoti* to explain to the auntie: the psychiatric hospital will not be a place to dump him. They will only keep him for a few months, so that he can be away from the *dagga*, and take his medication regularly until he is stable again. Then he can come home, and hopefully then he will be in a position to remain well. I feel this is the only thing that will help now, and I want to encourage the family to take him there. The *makhoti* replies:

SISTER-IN-LAW PD: *Yoh!* This is the first time we get someone who is explaining like you – but we’ve got it now. If you explain like this, then we are happy...

But it sounds a little too much like what I might want to hear. Once again, I have assumed that correct information, “understanding”, will resolve the situation. I haven’t touched the heart of it: it did not occur to me that leaving Phindile in hospital indefinitely might have seemed a better solution.

* * * * *

There is no neat ending to this story. The data generation period ends, and we leave Phindile where we found him: wandering, dirty and poorly clothed, watched with fear by his family and their neighbours. I go over the cycle again and again, looking for what might break it; I have nothing to offer.

⁶¹She is *udadobawo*: sister of their father. Xhosa families differentiate between the siblings of their mothers and their fathers, and different seniority and roles are assigned to each.

⁶² Like many other illnesses, mental illness is often treated using traditional medicine in this community, although individuals differ in their attitudes towards it.

⁶³ Traditional healer

The “Tree of Mental Illness” that caught Xaks’ attention in the hospital is playing itself out: alienation, alcoholism, resentment, isolation. While the healthcare workers may conceivably repeat their procedural loop almost indefinitely, the family and community cannot sustain the situation. The sister-in-law has refused to return to the hospital, the brother has given up. Rumours are circulating that Phindile is now wanting to rape, and perhaps it is only a matter of time before he secures himself a police lift back to hospital. The family has little incentive (or means) to engage with the health service again unless there is such a crisis.

Both Nozukile’s story and Phindile’s demonstrated a common pattern in the engagement of healthcare workers. Xaks summed it up like this:

XAKS: In Xhosa, we used to say, “*Ugqithisa itole kunina*”. *Itole* is a calf of a cow. At night you separate the calf and cow, so that you can milk the cow in the morning. Then in the morning if you don’t want to milk the cow, you just let the calf go straight to the mother so he can suckle. *Ugqithisa* means to allow him to pass, to allow the calf to go to its mother... So you are there to milk the cow, but instead you are just letting the calf through, not milking. You look like you are going to do your job, but you are not actually doing it.

This quote captured the essence of PHC workers’ engagement in the participatory spaces, as we observed it. While certain healthcare workers broke with the pattern, most of our participants’ stories reflected a going through the motions, rather than real engagement with the situation. Some participants, like Nozukile, continued to seek help in the hope that “one day, I will get the doctor who will understand my problem”. Others disengaged entirely. One elderly lady, Iris, who had become paralysed from the waist down many years before, informed us that she hadn’t been to the clinic since 1975. While she gave transport costs as the reason (she would have had to hire a private car for R50 or more for one visit), she was clearly also disillusioned with the care she had received in the past. Seemingly, nobody had explained her condition to her, and the pills she had been given had made no difference (she could not say what the pills had been for, but saw no help in them as they had not restored the use of her legs).

Mamthuli, whose story was told above, had similarly given up on looking for help for her son.

MAMTHULI: I have forgiven [those who did not help me]. I have accepted that God has given it to me to stay with my son as he is.

In addition to the years of “stretching” at physiotherapy and the unsuccessful operation, he had also been refused a place at the nearest school for learners with disabilities, ironically because he was unable to wash and dress himself, and there were no carers in the hostel to assist him. When his mother attempted to apply for a wheelchair for him at the district hospital, she had simply been turned away, because there were no chairs available. The string of failures and disappointments was almost unbroken.

It was not only in the more central services that this was occurring. While sometimes the healthcare workers’ approach could be attributed to their physical and social distance from the rural context, similar patterns emerged (although to a lesser extent) in community-level services.

It was not only in the more central services that this was occurring. While some of the healthcare workers’ approach could be attributed to their physical and social distance from the rural context, similar patterns emerged in community-level services. The story of Nontombi and her disabled daughter shed light on how and why this might be happening.

4.1.3. Nontombi⁶⁴: the mother who hides

We first met Nontombi during the previous research project, when a few of the community leaders who worked with us, brought her and her daughter, Nolufefe, to one of our workshops. Sixteen years old but looking more like ten, Nolufefe was born with severe intellectual and mild physical impairments. She also had epilepsy. Like the story of the family that eats the grant, we often heard about parents hiding away their disabled children, because they are ashamed of them. We were informed that this was one such family, but that once Nontombi had been in the workshop, and heard about the rights of people with disabilities, things had changed, and she was no longer ashamed of her child.

Naturally, a year on from this, we were curious to see what had happened in the household. The local *nomakhaya* explained to us where to find them, and we stopped by to introduce ourselves and ask a time to visit for an interview. Nontombi seemed suspicious at first, but Xaks set her at ease with his usual skill, and she seemed happy to agree to a date when we could return.

On the day of the interview, any warmth we had seen in her before was gone. She was closed, defensive, and we hobbled through our questions, receiving brusque answers and feeling acutely uncomfortable. I wrote later in my fieldnotes:

“When we asked for a story of a recent health-care visit, she didn’t come with a particular story. The first thing she told us was that when they go, she has to carry the girl all the way up the long hill road, about 6km of rough gravel, to the road where the transport passes. It was obvious this is a huge hassle: Nontombi is very slight, and even a ten-year-old-sized child is heavy to carry.

“The next thing was that she sometimes goes to Kwabisi clinic (closer and officially “their” clinic) and sometimes to the clinic in the neighbouring area. The reason for this, she says, is that Kwabisi doesn’t always have the drugs they need - something we haven’t heard before. And not sure why it would be different between clinics?

“She says she has no problem taking her child out in public ‘because I’m her mother’ (no reference made to coming to the workshop, or that she might not have done this before). Nolufefe can’t feed herself and isn’t toilet-trained, so is totally dependent, but she says ‘it’s not hard to care for her, because I’m used to it’. No accessing emotions there! I began to wonder what was going on, because the previous time she had warmed up to us, and this time she didn’t at all. Then we found out why.

“Xaks asked her if she had any fears for her child. (I was stumped - didn’t want to keep tapping into the negative stuff, but he offered the question before I could intervene, and it was the right one). She is afraid of Nolufefe being raped - because last week Monday some young men came to the house and beat up her 11-year-old son. No known reason. She is alone with the kids and her mother, her husband died a few years ago. They laid a charge, and the boy (not sure which or all) ran away. The police came (at least) and left a message at his home for him to report to the police station. Today was the day he was meant to go to town, and they are waiting to hear what happens to him. She wants to take Nolufefe to Johannesburg to her

⁶⁴ This was the only relative I chose to give a name in the stories, rather than a reference such as “FATHER AY” (Father of Ayanda). In this story, Nontombi plays the main role, as she mediates between her family’s needs (including Nolufefe’s) and the health services.

father-in-law, where a younger daughter is schooling. But what about her husband's livestock, and the boys? She doesn't know what to do." (Field notes, round 1)

When Nontombi began to speak about this, she became animated and engaged for the first time. Our questions about taking Nolufefe to the clinic suddenly seemed inconsequential by comparison. Then she floored me with this:

NONTOMBI: After all these questions you are asking, what are you intending to do for us?

It was what I dreaded hearing in all these interviews, although no-one else put it as directly as she did. The sense of taking people's stories and giving nothing meaningful in return was acutely uncomfortable for me, and clearly drove my ongoing attempts to fix things, even where this wasn't in my power, and possibly interfered with the research. On a deeper level, her remark also touched on the helplessness I felt here. Even as I came to understand each situation more fully, the solutions I had held onto in the past were revealed as facile and useless, and no new ones presented themselves. It was an extremely difficult place to be, and I had nothing helpful to say to her.

When Xaks and I discussed the visit afterwards, we both tried to put our finger on what had made both of us so uneasy throughout, even before her question. He suggested it was because Nontombi was not familiar with research, while I wondered if it was because she was uneducated. It was clear from the bare hut in which we had spoken that the family was dirt-poor, and she had struggled to read and to sign her name during the consent process. Once we had the story of the attack on her son, we decided it was because she was preoccupied with this fear. But we came away still confused, wondering what it was we had seen.

Several months later, Xaks visited again, to hear how things were going. This time he heard that Nontombi had stopped taking Nolufefe to the clinic back in 2000, even though her fits seemed to be increasing. He asked her:

XAKS: But if you say that Nolufefe is fitting every day now, why is it that you have not taken her to the clinic?

NONTOMBI: I didn't think that I must proceed, because this thing [of fitting] is going to be finished.

XAKS: But it is continuing. What are you thinking now?

NONTOMBI: No, I just leave her fitting, and then she finishes. I am just watching her, until she is finished.

It's a disturbing picture. Xaks also notices that Nolufefe is dirty, her nails long and her hair unkempt. He suspects that "what is happening in this house, they are just eating the grant". It certainly seems the mother has made the effort to take Nolufefe to hospital when required to obtain and keep the grant. At the same time, given the obvious poverty in the house, we can hardly accuse her of benefitting unfairly from the money. While the apparent physical neglect of the girl seems suspicious, I weigh it against the heavy work in which Nontombi is always engaged when we see her: going to the forest to collect wood, carrying water, doing laundry. The only other adult in the house is her mother, and I'm unsure whether her three sons, all under twelve and attending school, would help her much with what is commonly women's work. Survival seems a full-time concern, which could also explain her lack of enthusiasm for seeking health services.

Then this emerges:

XAKS: She also said her husband died of TB, and she suspects she has TB as well. So she also needs to go to clinic. Maybe the reason she didn't want to go to Kwabisi clinic is that the *nomakhayas* from the other clinic don't come there [to her area]. It seems like she wants to hide everything from others, doesn't want people to interfere.

Now it looks different. TB in this area too often means HIV⁶⁵, and this would explain her unwillingness to go to a clinic, where she would be tested and her status made known, in the presence of possible neighbours and relatives. While confidentiality is an official principle of care, in this setting it is impossible, especially given that the healthcare workers themselves might be the very people, in her social world, from whom she would want to keep such information. It is the *nomakhayas* who pose the greatest threat: residents of the community in which they work, they are widely mistrusted for their potential to gossip, and in their travels from one house to the next, to carry secrets where they shouldn't go.

But the question of Nolufefe's well-being is pressing, whether or not an adequate explanation exists for her apparent neglect. Xaks reports the situation to the clinic manager, Mrs Magida, as well as to one of the men who had brought the mother and her child to our workshop. Ethically, this seems the right course, not only from a legal perspective but also in terms of keeping the good faith of our partners.

Mrs Magida sends the *nomakhaya* allocated to this area to visit and bring her a report. Xaks later interviews this woman.

NOMAKHAYA 2: I was calling Nontombi before we went there, saying, we are *nomakhayas*, and we are weighing the children. Do you have a child that is small that we can weigh? Because we are coming to your location, not especially to your house.

It is clear she does not want the mother to think she is being checked up on. Apparently, the visit of a *nomakhaya* is not a neutral or universally accepted event, and this woman and her colleagues must take care to approach new households softly. The weighing of children is a new development, Xaks tells me, brought in with a National Department of Health initiative called Re-engineering Primary Health Care. Under this plan, community health workers such as the *nomakhayas* of Kwabisi, have been given some additional tasks, and come under the spotlight in clinic performance reporting and measurement.

The *nomakhaya* visits Nontombi's house with two colleagues. She explains that when visiting more remote locations such as this one, they prefer to travel together for safety. I picture the three of them arriving, a delegation.

NOMAKHAYA 2: When we arrived, we discovered in that home that Nolufefe is fine, she is clean. Maybe the parents were preparing, because they knew that we were coming. Then we asked for the clinic card and found Nolufefe is not taking any treatment. I noticed that in the card, the nurse said that they must go to hospital to see the doctor, on such a date. And afterwards she must go to the social worker at the hospital. Then I discovered that this mother didn't do anything. I passed the book to my other colleagues, so they can see too.

⁶⁵ Tuberculosis is rife in this area, and especially affects people who are immunocompromised, resulting in a high rate of co-infection with HIV (also common in this area).

At this point, I think, there can be no illusion on Nontombi's side that this visit was by chance.

NOMAKHAYA: She went to the doctor at the hospital, to have the grant renewed, but she didn't go to the social worker. I asked, why did you not go back to see the social worker, because you went to the doctor? She said, I didn't have money that time. And I said, what do you mean you did not have money, this child is having her own money that is coming every month.

It is not clear why Nontombi was referred to the social worker, or whether either Nontombi or the *nomakhaya* herself know the reason. But the community worker has picked up the trail of the grant-eating story. Although she cannot be blind to the logic of an impoverished household sharing the income of one member, she turns grant orthodoxy on this mother. To me, there is a subtle accusation in what follows:

NOMAKHAYA: I said to her, we are here for the children, that's why we are here, because they are disabled. We want to understand.

I can't deny having taken the same stance on occasion. Your child has rights, and I am here to make sure you honour them. Subtext: you cannot be trusted to do the best for your child.

She pursues the question of the clinic:

NOMAKHAYA: I asked her why she is not using Kwabisi. She said there is no *guru-guru* that is going that way, because when the *guru-guru* comes past her place, it goes straight on to town, and past the other clinic, not back to Kwabisi.

This makes sense. Public transport from Kwabisi consists of only one or two vehicles travelling to town each day, and these will only return late afternoon. As Nontombi's location lies between Kwabisi clinic and town, she will not find a *guru-guru* going in that direction until it is too late to visit the clinic. But the *nomakhaya* does not give up.

NOMAKHAYA: I said, but there is the car of Mr Q that is going every day from your location to Kwabisi clinic.

Mr Q is the chair of the clinic committee⁶⁶, and therefore obviously a person of some standing. I wonder what it would be like for Nontombi, a widow with little education and even less wealth, to ask him for a lift. Would he charge her? When I have seen local car-owners driving in the area, their vehicles have not been laden with passengers. I also know that cars owned by locals may be hired out as "specials", for hundreds of rands per trip, by those unable to use public transport to reach health services – as Nozukile described doing.

I also wonder why the *nomakhaya* is so insistent on Nontombi using her nearest clinic, Kwabisi, in spite of the obvious logistical difficulties. Xaks conjectures that the *nomakhaya* needs more "clients" to monitor. On Fridays he says, when she reports to the clinic sister, she is commended if she has many clients, and is then more likely to be chosen to attend training courses. Apparently, the *nomakhayas* who get more training, are given a higher stipend. It later emerges that competition is developing between them, even between the clinics themselves, over the right to monitor households in the various locations. It is possible that the government's community health worker policy is putting pressure on the clinics to produce evidence of this kind of activity, although it is not clear to me what exactly the *nomakhayas* have to offer the households they visit. In other households, where we have

⁶⁶Health facility board

asked about their assistance, we have heard only this again: they told us to take the sick person to the clinic.

The *nomakhayas* get no satisfaction from Nontombi on this visit, nor on their subsequent ones. She tells us:

NOMAKHAYA 2: With this lady, you can't tell her something, because she is not listening, although I was advising her to come to the clinic. That person is one who is very difficult, because if you advise her and she says she is going to do this, it ends there. If she says I can't take your advice, it ends there. Even if she says yes, she doesn't do what you are advising.

Finally, Mrs Magida, the clinic manager decides to go herself, to see this woman. She tells Xaks:

MRS MAGIDA: I was taking my car with my petrol, not the government car, and going to that house and try to understand. I was going with Mr Q, who is the chairperson of the clinic committee. And you were already coming to that house, you know the problem of that house.

The story of taking her own car, with her own petrol, is a familiar one to us. Mrs Magida is widely commended in the community for this extra sign of commitment, that she uses her own resources particularly to procure supplies of medication, when the standard deliveries fail (a frequent occurrence in this district). It only occurs to me later that our uncovering of problems in this household, within her catchment area, might have been considered by her to be a slight to her reputation.

Xaks reflects on the situation, unchanged by the intervention now of three different parties: ourselves, the *nomakhayas*, and the clinic manager herself.

XAKS: In fact, me and Mrs Magida and the *nomakhaya*, we end up seeing different things. For myself, I see that since Nontombi doesn't have the information [she is not educated], it was not easy for her to accept the advice that she is given. And she knows how to treat her child if she sees the seizures are starting. The *nomakhaya* discovers that mama is hiding her problems and she considers that Nontombi's mind is not right – maybe there is a problem in her mentality, because she doesn't accept help. Mrs Magida, she doesn't see the problem in that house, only that the mother is enjoying the grant her child is getting. Otherwise she knows the steps she can take for her child when she is not well.

Each one's interpretation of the situation serves her own interests. The *nomakhaya* judges Nontombi for not accepting her offer to help carry Nolufefe to Kwabisi clinic, where she (the *nomakhaya*) would be commended for having succeeded in bringing her in. Mrs Magida has demonstrated (most particularly to me, I feel), that she is indeed the diligent and dedicated leader here, and she dismisses the concerns we have raised as unfounded: we have not, after all, identified a lapse in her vigilance and care.

This is when he draws the comparison with the calf and cow: each is appearing to do her job, but neither actually helps the household, because their concerns are elsewhere. I have to wonder: what help is actually needed? And who could provide it? It was the question Nontombi had asked us, and I still had no answer⁶⁷.

⁶⁷ It should also be asked what our own interests were in this situation. We wanted to understand what was going on, but we were not disinterested observers. Nontombi's question itself highlighted the impossibility of this: asking questions conferred responsibility, both the ethical one of a healthcare professional to report ill-

Xaks' interpretation echoes the feeling I already had, that the activities of the *nomakhayas* are missing their mark. I cannot blame them: given their cursory training and the logistical challenges of their job (particularly transport), it is not surprising at all. At the same time, their formal tasks seem to be more about surveillance, collecting information and reporting this back to the clinics, than intervening.

It makes me wonder, then, how people receive them. Are they welcomed, when they come to ask questions, to collect information that will be reported to the local authorities? Because it is now clear that Mrs Magida herself is a respected community member, although strictly speaking not a full resident⁶⁸, and that she works closely with the local elders and community leaders. Whereas previously this appeared to me to be the "community participation in health" aspired to in policy, I now see how unwelcome it might be to a household wishing to preserve its privacy and autonomy.

The *nomakhaya's* report of her conversation with Nontombi reflects much effort to appear "on her side":

NOMAKHAYA 2: I told her, as I am a *nomakhaya*, I am available to assist you to carry the children. We can't give up on this, because your child is still young. This is the job of the *nomakhaya*, to assist people like you. If you have a transport problem you must come to me, and if you need help to carry the heavy child I can help you, because *nomakhayas* are here to help, to share the burdens⁶⁹ of the people.

She also attempts to recruit our help to strengthen her position:

NOMAKHAYA 2: If you, Xaks, when you go around, you see the second hand clothes, if you can give to them, it can help. Because the money that they get, it seems it is not enough because there are many children. Please don't forget, if you have the uniforms or other clothes, to take to that house, so that they can see that we are with them.

To me, it seems as if she feels the same helplessness I felt in this household: asking questions, but unable to offer much in return.

The struggle for acceptance by their clients is a universal one for the *nomakhayas*. Another woman comments:

NOMAKHAYA 3: The thing we are facing is this. If we pass the message that we are coming to that house in the community, there are people who don't want us to come, because they say we are undermining them.

"Undermining" means that a *nomakhaya's* visit might damage one's reputation, one's status in the community. To receive a visit of "help" from someone of a lower status and education than one's own, is unacceptable.

treatment of vulnerable people, and the interpersonal one of reciprocating what Nontombi shared with us. Although my desire to fix things was not the best stance, the positivist position of a detached researcher who simply observes was even less appropriate.

⁶⁸ The clinic nurses have accommodation at the clinic, where they stay during the week. Most return home on the weekends only, as their homes may be several hours' drive away.

⁶⁹ She uses the word *ukoyisa*, which literally means to help to lift something heavy: here it has both literal and figurative meanings.

XAKS: Like me for example, I won't accept *nomakhayas* to come in my house. I can say, please pass. Because if I have a problem, I can solve it myself, I can phone the academics⁷⁰ who know about this thing.

There is another aspect to this:

XAKS: The professionals [and other people of standing] are expected to have medical aid⁷¹, not needing *nomakhayas*. There is a stigma with the *nomakhayas* coming, because it means you don't have medical aid. Like me, if I am going to hospital, people laugh: "You are working with whites, you are working in a nice place, why don't you have medical aid?"

So the *nomakhayas* don't have sufficient training and professional standing to elevate them automatically in the social strata by which community relations are ruled. They must depend on the status they otherwise have, whether by position or wealth or reputation, to be considered acceptable advisors:

XAKS: Whether a *nomakhaya's* advice can be accepted, is depending on who she is in the community: if she has status, is someone who is behaving right.

Xaks also feels that they would be better received if they did not work in their home communities:

XAKS: In our culture, it's easy to accept the thing that you grew up knowing⁷², if it comes from someone from outside. They can think it's the messenger from God. An outsider can't just come to you and talk nonsense to you. Maybe if the *nomakhayas* from this community can work [in the neighbouring location], and then those from over there can come and work here, then they can be treated with respect.

At the same time, a visitor from outside the immediate community poses less risk of exposing household secrets:

XAKS: You can allow [the person from somewhere else] to come and check your cupboard⁷³, check your neatness. So if they chat [gossip], then they chat far away, that news won't come back to you. Because even if you are going to the toilet, this one [who lives in your own community], can see you.

His remark brings home to me how public private life is here. Much of life is lived outdoors: collecting water, cooking on a fire, even relieving oneself. If one goes to the clinic, goes to town, one's movements are immediately visible, whether one walks or uses the *guru-guru's* crammed with one's neighbours. It's an implication of the lack of infrastructure and services that I hadn't previously

⁷⁰ He is referring to the UCT occupational therapy researchers (including myself), as well as other researchers with whom he has worked over the years. It is clear from many of his remarks that his highly visible and long-standing association with white people from the universities, elevates his status substantially.

⁷¹ Private medical insurance, the chief means of accessing well-resourced private healthcare. Given the stretched state of state healthcare, medical aid is held by almost everyone who can afford it, although this works out to less than 20% of the population.

⁷² Often, the advice dispensed by the *nomakhayas* is "traditional advice", not drawn from specific training.

⁷³ "Your cupboard" means what you are eating, which obviously also reflects your economic status. "Your neatness" refers to cleanliness, presumably of the house as well as of its residents themselves. While both nutrition and hygiene are widely promoted as "healthy behaviours" across the board, the way Xaks phrases this emphasises the moral overtones of these directions. The idea of having one's home "checked" in this way, particularly by a neighbour, makes it clear how condescending and potentially intrusive such interventions might seem to those who receive them.

considered. In the face of all this non-negotiable exposure, it is easy to see how unwelcome extra scrutiny might be.

What is also evident here is the compaction of all of life, into the same social spaces. One's neighbours are met not only at home, but on the road to town, in the clinic waiting-room, at the grant pay-point, at church, at community meetings, and at social events. If one has a job of any kind, it will most likely be a piece-job for someone else in the community, or a turn at a state public works contract⁷⁴ alongside those same neighbours. It must take strenuous effort to keep any matter private in such a setting.

It is also possible that a *nomakhaya* working outside her home community will not be preoccupied with her own social standing while going about her work. Xaks reminds me of the *nomakhaya* who had visited Mamtuli, after we had written a letter motivating for her to receive a grant-in-aid. The *nomakhaya* insisted on taking the letter away with her, saying she would deliver it to the SASSA⁷⁵ office when she went to town. Xaks suspected she took the letter because "it's written in English, and it's written by Kate", and it would impress her colleagues. When Mamtuli followed up with her, she had lost the document.

All of this strengthens the feeling that the *nomakhayas'* position is tenuous, vulnerable. They are caught between their employer, the health system, and their own communities, who contest their right to do the work they are sent for. Far from being a form of empowered community engagement with the health service, in this case community health workers are imposed on the local population, their duties dictated by policy-makers in distant cities. With the increase in pressure on clinics to send *nomakhayas* out, and to report on their activities, it is clear the nurses are demanding more from them, unfortunately without equipping them with additional skills and knowledge (not to mention practical support) to do this work effectively.⁷⁶ One cannot blame the nurses themselves: there are no additional staff allocated to train and supervise these workers, and the most significant challenge, transport, has been raised by the nurses repeatedly, with the district officials, with no response. The *nomakhayas* themselves have no avenue to raise their concerns: one makes this somewhat pathetic request of Xaks:

NOMAKHAYA 3: Hey *bhuthi*⁷⁷, if you can try and assist us with who is the manager of the *nomakhaya's*, actually? Because if we have things we don't like, the complaints, things we want to talk about, we don't know who we must talk to. If we talk to this one, she says no, you are under that one. And that one say no, you are under this one. So it's like a game.

At the same time, they are held responsible by their "clients"⁷⁸ for failures of the health services at other levels:

⁷⁴ State contracts for road maintenance, building of housing or public facilities, and so on, generally employ local people for unskilled labour. Contractors negotiate with local leaders to allocate such jobs, which are highly sought-after, and usually each household is given an opportunity for someone to work a week at a time, by rotation.

⁷⁵ South African Social Security Agency, the body that administrates welfare payments

⁷⁶ The pressure is not just from the district managers to whom the nurses report, but ultimately from the national Minister for Health himself. Community health workers are the cadre tasked with carrying "re-engineered primary health care" into communities, towards the goal of "health for all".

⁷⁷ "Brother"

⁷⁸ "Client" is the term the *nomakhayas* use for the households they visit. The nurses seemed to use both "client" and "patient", although the latter was more associated with services provided at the clinic or hospital, rather than on an outreach basis.

NOMAKHAYA 3: People keep on commenting back to me, because if I send someone to the clinic, and the clinic sends them to the hospital and they don't get help, they can come back to me to complain.

A community member concurred:

FATHER AY: People can ask [the *nomakhaya*] why are you sending me there, while I'm using a lot of money to go there, and after that I didn't get help?

It is an embattled position these women find themselves in, particularly in a province where the public health care is well known to be poor. On top of this, they must walk long distances to see their clients, regardless of weather, and in some areas risk being robbed or attacked. I find myself wondering, with all these factors, why they continue. One woman tells us:

NOMAKHAYA 3: Although our work is strenuous and stressful, and people are looking down on us, we are devoted to what we are doing for the people, and we are working hard, and we are trying to help the people. And we see at least we are making the difference.

At the same time, we are well aware that opportunities for income, however small, are desperately scarce, and not easily passed up when offered⁷⁹. The *nomakhayas* may be criticised for questionable effectiveness, for breaking confidentiality, for interfering where unwanted, but they too are pressed for survival, both economic and social.

I return to the situation in Nontombi's household: although still opaque to us in many ways, it is at least clear enough to overturn simple judgments of neglect and exploitation. I regret exposing this woman to scrutiny, simultaneously wondering if we have done enough to protect Nolufefe and ensure her needs are met. What else could be done? A visit to the clinic would merely result in a referral to the hospital, where Nolufefe may or may not be prescribed the most effective medication for her fits on initial assessment⁸⁰. Should the right treatment be established, Nontombi would then need to visit the clinic monthly to collect the drugs for her child. Hospital review visits are generally required every six months for scripts to be renewed, and clinic staff might require more frequent review of Nolufefe in person at the clinic. It is an enormous amount of effort, for what might seem unlikely or insignificant gain. Nontombi will have long given up any hope that Nolufefe could ever be capable of more than she is now; she is "used to it" being like this. Fewer fits, in her eyes, will potentially change little in their lives.

What other services might Nolufefe have a right to access, that we should be pushing for? Special schooling is scarce enough to be unlikely, especially given her age. Nontombi mentions that she asked the local principal about this possibility in the past, but did not pursue it for fear of losing Nolufefe's grant to school fees and transport costs. One might protest that the child has a right to education and that this is the purpose of the grant, but again, in the context of this household, I can see how it makes little sense. Nolufefe will never be employable, and even if she completes some years of schooling, her main contribution to the household will remain the disability grant. Better to use this money for

⁷⁹ Interestingly, this *nomakhaya* also described her family's unhappiness with her work. It seemed that both her husband and children resented the amount of time and energy she spent on something that brought so little reward. I also wonder if the uneasy position of the *nomakhayas* in the community affected their families' social positioning as well.

⁸⁰ Anti-epileptics often need dose adjustment and trial of various drugs and combinations before the optimum treatment is established. Typically, this does not seem to be conveyed to the patient, who may quickly give up on "the hospital medicine" if the first attempt is ineffective. It is also known for patients (or their family members) to avoid treatment for fear of losing the disability grant.

the school fees and uniforms of the three other children, who at least have a chance in future of being able to help support the household.

I can see how this situation would be read by the majority of disability rights activists and well-meaning healthcare workers (including myself in other times). This mother has negative attitudes to her child and she is violating her rights to healthcare and education. But can Nontombi do otherwise without sacrificing the futures of her other children, and possibly the survival of the whole family? This is not “eating the grant”: there is no trace of self-indulgence here, no undue benefit to anyone. But received wisdom (from where?) seems to trump comprehension of the context.

As in the story of Phindile, it is hard to settle on any villains here, despite our early judgments on the healthcare workers for “not helping”. They may be serving other purposes than those they claim, but they too have households who must eat, and in this community, one’s “dig⁸¹”, or reputation, is as critical to survival as food. The *nomakhayas* have been assigned a set of tasks by a distant policy maker, which not only prove almost impossible in this physical context, but also take on entirely different meanings in this social context. The result is, as for Phindile’s case, a cycle of apparently futile activity, with no perceptible solution to the real problems.

There is a disturbing postscript to this story. The *nomakhaya* reveals that there is another disabled child in the village where Nontombi lives, and she has also been hidden away: in the home of Mr Q, the chair of the clinic committee himself. When we raise this with Mrs Magida at the clinic, she brushes it aside. “There are many families of that name”, she says, and never, to our knowledge, follows it up. The *nomakhaya* is afraid to visit on her own, and asks Xaks to go with her. She takes seriously a new policy that the *nomakhayas* should visit each and every household, no matter the standing of the occupants. I suspect there will be no support from her supervisor this time, regardless of the rights of the child.

While Nontombi allowed the *nomakhaya*’s (and us) into her home, she evaded probes for information, and deflected the healthcare workers’ instructions by feigning assent. While the *nomakhaya*’s believed this reflected “a problem with her mentality”, her approach was in fact characteristic of our participants’ engagement with health services. Open confrontation or refusal was not feasible, so one kept quiet, appeared compliant, and went one’s own way out of sight of authority.

This approach was certainly a pragmatic one, as we had observed, but it also fitted the patterns of social interaction in this community. Hospitality was too important to refuse a visitor in one’s house, so “silent resistance” was the preferred strategy. Harmony in social relationships was paramount, and direct approaches to any topic at all were avoided, as reflected in the heavily idiomatic language, and use of implication rather than direct naming for certain topics (for example, when voicing his intention to go and see a traditional healer, one of our participants simply said “I am going to go out”, and in another instance, “I am going to meet a person”).

The silent resistance, from both Nontombi and others, often included us as researchers, although I only began to “hear” this in our interviews with Xaks’ help, long into the process. Some participants allowed us to interview them, but repeated the same brief story or explanation on each occasion, never responding to invitations to elaborate. One example was Iris, who simply stated that she never went to the clinic because she didn’t get sick, and couldn’t afford the transport. Even Xaks was unable

⁸¹ Short for “dignity”, and the term Xaks uses to refer to reputation and social standing

to elicit more of her story from her, and after repeated visits, he expressed the view that she was “hiding”, not wanting to engage with us.

This was a tacit exercise of agency quite different to the Western ideal of “engaged citizenship”. While the stories told above helped me make sense of this behaviour as an active and coherent choice, rather than simple passivity, one of our participants did in fact seem to behave exactly as I had expected an “engaged citizen” to do. Studying how he did this placed familiar disability rights ideas in context, showing up both their possibilities and their limitations in this setting.

4.1.4. Sibongile: First in the queue for *fonkonko*⁸²

Sibongile is a man in his mid-thirties, the head of a small household, and someone intent on building a better life for himself, his wife and their two children. He sustained some kind of lower limb injury in childhood, and walks with crutches. He is confident, active, and at the forefront of happenings in his location. In our previous research project, he worked on our advisory group⁸³ to organise and promote the workshops, and spoke up in every meeting. He is constantly on the move, doing carpentry jobs for neighbours, joining in municipal income generation initiatives, working on his homestead.

He tells us this:

SIBONGILE: Let me not lie, *Zulu*, I used to wander, doing nothing. Having no idea as to what the DPSA is, and I used to drink a lot, *Zulu*. It dawned on me when I came across DPSA, I saw a way to the real life. I told myself that I won't throw away this.

The DPSA is Disabled People South Africa, an organisation run by people with disabilities of all kinds, which mobilises its members around the international disability movement's slogan, “Nothing about us without us”. It is strongly rights-focused, and speaks out against the domination of people with disabilities by others, including professionals and family members. A few years previously, DPSA representatives had come to Kwabisi to recruit people with disabilities to form a local branch, and to learn about their rights. The leading figure was an older man from a town near Mt Frere. Meeting him was a turning point for Sibongile: from spending his time smoking *dagga* and drinking in the shebeens, he moved to finding a wife and starting a family, building a homestead, and setting about becoming a respected leader in his community.

He tells us about his current activities:

SIBONGILE: Now that I have [my own] carpentry tools, I am able to get some jobs here and there. The most important thing is getting jobs. Even if I can get a six months job. Because I save this money, it belongs to my wife and children. I am only left with R200 just to buy the glue [for my business], to support myself. My wife has an association⁸⁴ with other women in

⁸² *Fonkonko*: something poorly made and easily broken – cheap junk

⁸³ The advisory group included Gogo, Sibongile, a community development worker, and a number of other elders in the community. They assisted us with planning and organising each workshop, and were tasked with carrying on the work of promoting disability rights, in whatever way people decided was valuable.

⁸⁴ “*Umgalelo*”: also known as a *stokvel*, this is a community savings scheme in which each member makes a monthly contribution, and receives a share of the savings at an agreed time, either on a rotational basis or at the end of the year for Christmas groceries. Most women in this area belong to such a scheme, and they are a crucial way of raising enough capital for larger purchases.

the community. There are also burial society⁸⁵ and things like that. Children have to eat. If only I can get money that I can use for business - even if I can get a job for R1 500⁸⁶, I would use R500⁸⁷ for my business...Yes, *Zulu*. I've got many plans but nothing seems to work so far.

He has continued to be involved with disability-related activities, although the local DPSA branch seems to have fizzled out. The local municipality has sponsored skills training for people with disabilities, and he has learnt carpentry and business skills, also getting to know a number of other people with disabilities in the wider area. He tells us about a cooperative he is forming with some of these acquaintances. Forming cooperatives seems to be the approach favoured by municipal income-generation schemes at this time, although it isn't entirely clear what they are intended to do. According to Sibongile, any group can form a cooperative, they simply need to pay a small fee and register their name with the municipality. Then, when income generation projects are planned, registered cooperatives can apply to participate.

SIBONGILE: That is why I have this group, they are clear as to what they want. They really want to work. If I can remember well we last met one another in June last year. We are planning to work together in the project, but the problem is that they don't want to pay the joining fees. I am going to pay the money because I am planning to do this business and then start my own.

Although he says here "they really want to work", he is also indicating the tensions of working with others. While institutions such as *imigalelo*⁸⁸ and burial societies seem to run smoothly in this community, other types of collective effort don't follow naturally. Every government-initiated activity seems premised on groups coming together to work for shared benefit, but we see far more derelict and abandoned "projects" than functioning ones. Some locations even have fields of maize, ploughed with government-sponsored tractors, seed and fertiliser similarly provided, intended for collective tending, until the harvest can be sold back to the government and the profits distributed. Xaks points out to me that these fields can always be identified by their weeds: no-one wants to work on something that belongs to everybody. Xaks also tells me:

XAKS: [It's like this] because always, someone will go with the money, the supervisor will just disappear. People are tired of that.

It's true, we hear this story again and again: the business was up and running, people were working together – and then someone ran away with all the money. Sibongile sees it slightly differently:

SIBONGILE: What makes [other people with disabilities from the area] lack in thinking about making money, is the lack of knowledge on their part. Or what could be the other reason for not thinking? They are not thinking about life, *Zulu*. People are thinking about their pigs, they say they can't leave their livestock and go to work for something that belongs to everybody. That's why I said lack of knowledge is the problem.

⁸⁵ Similar to an *umgalelo*, although some burial societies are commercially run rather than by the members themselves. Funerals are enormously significant events in this culture, being an honouring of the dead, who are joining the ancestors and will forthwith oversee the fortunes of the family. They are also displays of status, intended to maintain the "dig" of the family in the living community, and to honour the ancestors in the broader cosmological community. A respectable funeral happens over multiple days, involves the slaughter of cattle, the feeding of the entire community, and the purchase of appropriate coffins, tombstones and so on. Such a funeral, at the time of writing, would cost about R50 000. Burial society membership is considered an absolute essential, even among the very poorest people.

⁸⁶ US\$95

⁸⁷ US\$31

⁸⁸ Plural of *umgalelo*

I'm not sure what he means by "knowledge", although I know that the isiXhosa word, *ulwazi* may also mean understanding or perhaps education. Certainly Sibongile himself seems to have attended a fair amount of training of various kinds. When we ask him where he learnt his confidence in speaking up as a person with a disability, he tells us:

SIBONGILE: Workshops helped me a lot. Like the one I attended [at the municipality] between 2008 and 2009, where a government representative from East London taught us about how a leader must behave, to have confidence, attend meetings, do not be scared to express yourself.

He obviously takes this seriously, and we know that he has served on the steering committee for his location. I wonder how many other people with disabilities attend public meetings.

SIBONGILE: No, they [disabled people] are not attending regularly, their attendance in these meetings is still the same ... Most of the time you will find that the people who attend are the ones who have disabled children themselves... You find that the disabled person wants to attend the meeting, but due to his or her condition he is unable. Those who can walk, they do attend.

He is also speaking about the meetings organised specifically for people with disabilities and their families by DPSA or the municipality. Certainly during the previous research project, held at the Great Place⁸⁹, a number of our regular attenders (Sibongile included), had to be fetched for meetings by Xaks in the car, because the walking distance was more than they could manage. It's clear that organising people with disabilities to work together, whether on an income generation project or to lobby for their rights, is logistically extremely difficult, whether people are enthusiastic or not.

It makes sense then, when it emerges that Sibongile mainly attends meetings where opportunities for local employment are discussed: for him, disability rights are "a way to the real life". He is vocal about the importance of employing people with disabilities – to the extent where Xaks and I wonder if he feels that every job should go to a person with a disability. Around the time of our first few discussions, there are plans afoot for a dam to be built in a nearby location, as well as work being done on the roads. Sibongile is open with us about his distress that people with disabilities are not being employed in these projects. But he is clearly taking a stand.

He describes to us how he is approaching this challenge:

SIBONGILE: In the tribal meetings I can talk now, on behalf of the disabled people, that whenever there are employment opportunities, the disabled must be considered as well...because I used to be the secretary in the tribal authority.....and then I decided to quit, but I always invite them when we are visited by this guy, Mike from [Department of Labour]. People from [my location] were present, and they know the law in terms of how to treat disabled people because they attended⁹⁰.

Two things are clear from this statement: firstly that his status as a previous office-bearer adds to his confidence and authority to speak up, and secondly that he requires corroboration from others in the meeting, for his claims on disability rights to have purchase. I had not considered before that such

⁸⁹ The Great Place is the headquarters of the chief for the greater area (here including eight or nine smaller locations). All major gatherings of the community, including the tribal court and the *imbizo*, or weekly meeting for all tribal business, are held here.

⁹⁰ He is referring to one of our workshops, where this gentleman from the Department of Labour came to speak about the right of people with disabilities to work.

claims bring one into direct competition with one's neighbours, all of whom are equally desperate for income. As in the clinic waiting-room, these others are not strangers, but people with whom one may have long-standing and multi-faceted relationships. I began to notice how skilful Sibongile was in recruiting authority and other reference points to strengthen his position. Far from being oppositional or demanding in his claims, he was careful to nurture consensus and approval:

SIBONGILE: You don't have to sit quiet, *Zulu*. Silence is wrong, but with our advisory committee, I don't think there is anything that can stand their way, as I have confidence in [three senior members]. If there is anything that is a stumbling block, I will call Mike because he gave us his number, but I shouldn't call him before contacting the contractor and the ward councillor. But I tried them to no avail, hence I called [the community development worker⁹¹]. Yes, I need to follow proper channels, I shouldn't just talk to other people without first talking to the appropriate channels.

He described a similar approach when claiming his right to be seen ahead of non-disabled patients at the hospital:

SIBONGILE: When I was there, I saw someone who was taking the blood pressures, and I told her my story, and I asked her for help, so that I mustn't sit in the queue because I am having heavy pains. After that she didn't answer me. There was a woman in the queue, and she stood up and spoke with the community, and said this guy is sick, seriously, let him go first, he mustn't stay in the queue. There was a guy who was in a wheelchair, and she was asking even him, and he didn't agree.

"The woman was asking the wheelchair guy, look this guy is in pain, you don't see that he is sick? And this guy still doesn't agree. So I came to the guy in the wheelchair and explained to him about our rights [as people with disabilities] – we can't queue. Because we have rights, if we are sick like this, serious. But still he is stiff⁹². And there is an old man who is in the queue and he said go, pass, and I passed [to the front of the queue].

Having experienced the hospital waiting room, I could understand the resistance to anyone claiming such a right. Initially I thought it ironic that he was claiming his right as a person with a disability, to go ahead of someone else with a disability (the man in the wheelchair), but then noticed how he backed up his claim with the seriousness of his suffering. I wondered if he would have asserted himself in the same way on other occasions.

He also had to negotiate the interaction with the nurse in a non-confrontational way, as the slightest perception of challenge to her authority might have turned her against him (as we had previously discovered):

SIBONGILE: There are also papers that are written there, according to the rules for the disabled people [on the wall in the waiting room]. I read it... when the sister told me to sit in front of the queue. Without talking to her, I was just reading there, and she saw that I can see my rights.

All this was a new angle on the idea that people with disabilities should "stand up for their rights". It hadn't occurred to me what risks this might involve, and even more so in a society where consensus, unity and equal treatment to everyone, was so central. It struck me again how strongly the rights

⁹¹ Community development workers are local residents, employed by the Department of Social Development, to implement things like income generation initiatives.

⁹² Stiff: unwilling to understand or agree

discourse is premised on an individualistic social order. In my world, someone might be admired for “standing up for himself”, even if his success disadvantaged others. In this one, such a person would be distrusted and even treated with hostility, unless his approach clearly affirmed social solidarity and respect for the social order. Sibongile evidently possessed a confidence that few others shared, as well as a level of personal authority and social skill that was unique. I wondered whether being male and the head of a household added to this; I suspected it did.

Although he seemed to be recognised as a leader among people with disabilities in his community, this did not mean he was able to transfer his gains to others. He told us how he had finally been given a week’s work on the road contract, and when it was over, had asked the committee to replace him with another person with a disability.

SIBONGILE: I had a chance to talk again, because I am one of the people on the steering committee, and I say my week is ending, and I want to put a person who is disabled in my place. Then the contractors say and the community people say, please, don’t talk about the people who are not here. Because you are the only disabled person who is here.

It seemed that only community members who attended these meetings were eligible for the work. In addition to the difficulties with transport, Sibongile had also complained that other people with disabilities were unwilling to make the effort as he was. He had tried to work on their behalf before, organising attendance at a computer course, but found that while all benefitted, no-one else joined him in working for it.

SIBONGILE: The main issue is that people with disabilities don’t come to the meetings. They come only when the thing is ripe.⁹³

As a result, he seemed to be called upon whenever a person with a disability was required to take part:

SIBONGILE: They employed me in the school as they said they are promoting disabled people, they felt that they also need to consider the disabled person. I repaired and fixed the doors and windows. That was something impossible before. We had disabled people who are skilled builders in the community. But they were not considered [when jobs needed to be allocated].

It was encouraging to note that the notion of disability rights was at least filtering through to the various institutions in the area. Sibongile raised another obvious barrier to this:

SIBONGILE: I hear from the contractor, he said he didn’t want anyone who is getting a grant from Government.

This makes sense: people who receive disability grants are perceived to have an advantage in income, although it was clear to us that this usually did not compensate for the cost burden of disability. In addition, the physical labour usually involved in public works contracts would have precluded many with physical impairments. When Sibongile is given his week of work, he is given the task of pacing out the loads of gravel dumped by the trucks, and recording these.

⁹³ *Umqha uvutiwe*: the term literally means, to be cooked to the correct point, for example when maize meal or pumpkin is ready to eat.

SIBONGILE: I am having a lot of pains. It is a distance to walk from my home to the place where they are working. Then when the truck comes I have to use my legs [to pace out the load size], and that makes me tired. But it's me who was asking for the job and going to work.

There is no room for him to complain. "Reasonable accommodation"⁹⁴ is too much to ask for a week-long job, where already he has pushed the boundaries to be included at all.

I was curious to know more about how he interacted with healthcare workers. Would he demonstrate more of the kind of empowered behaviour I had expected? Could he make this work?

It quickly emerged that he had a serious and ongoing health challenge, which caused frequent "heavy pains", drained his resources, and jeopardised his best efforts for "the real life". It came in the form of two small pieces of plastic.

SIBONGILE: The problem is when you don't have enough [crutch] rubbers. Because you walk a long distance, you see... and it happens that [your crutch] doesn't have a rubber... Now where is it pounding? This iron is causing pains straight here. It pounds on you...

"Sometimes I'm having back pain, and in the arms. When you walk on the gravel or tar road, you may find you get sores on your hands, because you are struggling when you walk. Other thing that is developing, is when you feel like you have holes in your back. Those holes are so painful when you are sleeping.

"Now, I was always lying down with the pain. I understood that I am also worried now. I am worried how I am going to work now for my child, for my children."

He walks on aluminium elbow crutches, and the rubbers he mentions are the stoppers on their ends. Also called ferrules, they give grip and shock absorption. In this setting, given the amount of walking he does, they also wear out in a matter of weeks, causing the problems he describes.

But it gets blurry when we try to find out how replacement ferrules can be obtained. It always seems to start with a trip to the hospital in town. He waits in the queue, and the doctor signs for his pills. Sometimes he is given a new set of crutches, because they don't have the ferrules as spares. Sometimes he sees a physiotherapist, who makes an appointment for him with the physio at the tertiary hospital in Mthatha⁹⁵. For this, he must be booked on the hospital transport, along with patients going for cardiology, ophthalmology, orthopaedics, and other highly specialist services. Patient transport from district hospitals is always overbooked, vehicles scarce and poorly maintained, so not always reliable. But Sibongile must come back to the hospital the day before his appointment, sleep over on the waiting room benches, and go with the other referred patients in the morning, early. At Mthatha, he is given a single set of ferrules.

The exercise takes three to four days, and costs over R100. During this time he cannot work, and his family is left alone.

SIBONGILE: The main thing that worries me is the safety of my family. There have been instances of rape and people being stabbed. And that day I was taken by an ambulance [to

⁹⁴ Reasonable accommodation describes the adjustments to task, workspace, building access and so on, that an employer is required by law to make when employing a person with disabilities, in order for him/her to be able to do the job successfully

⁹⁵ Nearest city, and the tertiary referral centre for the entire region, approximately 100km from Mt Frere.

the hospital], I arrived home at around seven in the evening. Someone came to knock on our door, not knowing that I am back already. When I answered the door from inside, he ran away... I fear for the safety of my family, because I do not even have burglar bars here...The boys come from the shebeens violent and they target households, raping, stabbing and taking money of those who stay alone."

He speaks to the manager at the clinic, and she writes to the district manager to ask for ferrules to be delivered to the clinic, with the drug supplies. The drug supplies themselves are notoriously unreliable. We hear later that he collects new rubbers here once, but then the supplies end. The clinic staff have taken his name and number, but he has not heard from them.

He makes other plans. A friend who works in Johannesburg comes with second-hand crutches for him. He suspects they were found on the dump. He prefers the ferrules from Johannesburg:

SIBONGILE: The only rubbers I am recommending are the black ones [that come from Johannesburg]. The grey ones are the Presta [name written on the gray rubbers], they are finishing quickly. I'm talking to you about the black ones, because these are the strongest, they take a long time to be finished.

"I think they make [the black ones] in Johannesburg. And the grey ones, the Presta, I think it's a *fonkonko*⁹⁶ – it's made in Eastern Cape."

On another occasion, he pays a neighbour R80⁹⁷ to fit his crutches with makeshift ferrules made from tyre rubber. I look up prices online, and it seems a pair of ferrules can be had for less than R20. But there is nowhere here he can buy them.

I remember the difficulties of obtaining supplies of ferrules from my previous job as a therapist in a neighbouring district. New crutches were not a problem, they could be ordered from the central pharmacy depot. We resigned ourselves to swapping out the entire crutch (over R100⁹⁸) when a ferrule wore out. The cost, after all, was borne by the district, not by us.

I email colleagues still working in the province. Yes, ferrules are still a problem. A physiotherapist friend is wrestling with it at the moment. We contact a pharmacist who used to work in the area and she advises us to try and use the direct delivery mechanism. It's meant to make things easier, because the depot deals with the supplier on behalf of the hospital. Then she explains:

PHARMACIST: Once you submit an order to the central depot, make sure you get your "yellow copies". This is a copy of the purchase order. I always used to follow up with the supplier because a lot of the times the depot would generate the order but it would never actually get to the supplier. [You can] call the supplier while you're at the depot, so that if they haven't received it then the depot staff can sort it out while you're there. I used to stage mini sit-ins until they sorted it out for me.

It reminds me what it takes, in this region, to get the simplest things to happen as they are meant to. I was used to working in a clinical team where this kind of effort was the norm, and this had a lot to do with my early judgments on the healthcare workers in our stories. But then I realise two things. Firstly, we were almost all white, all outsiders. Our behaviour did not make us popular with our local colleagues, but we could risk this, having a support structure of our own outside this group. Secondly, few of us lasted more than a few years in such jobs. You can only fight like this for so long. For the

⁹⁶ Something common, which breaks easily – junk

⁹⁷ US\$5

⁹⁸ US\$6,35

staff I met in Kwabisi clinic and the district hospital, especially the nurses, burning out was not an option, because what other work would they do? And who would support their families if they could not continue to earn? This reckoned even without the hostility one would face as a black healthcare worker seen by one's colleagues to fight the system, to do things differently.

We also learn that the ferrules are on the national walking aids tender, which means that they can only be sourced from the company to which the tender is awarded. After over an hour of internet searching, I find out that the tender was advertised for renewal several months previously, but has not been awarded. Shortly after, an email lands in my inbox: the various rehab professional bodies are writing a letter of complaint to the National Department of Health about this failure. I chip in the concern about ferrule quality for rural areas, which, although acknowledged, has never been addressed.

It's a spectacularly ironic story: our paragon of empowered engagement is literally crippled by the arbitrariness and dysfunctionality of the system. Not that he has not tried: he has approached the clinic manager, and she has done her best for him. What else could be done? It's an ideal issue for considering how the formal mechanisms for "community participation" might work. We know he has written for the complaints box at the hospital before, but this was on the question of doctor shortages and waiting times, not about the ferrules. There would be little point in raising this through the clinic committee, were it functional: the person to take action would still be the clinic manager. Why concern others with a personal, technical issue like this one? Better to take it directly to the healthcare staff.

It makes me think again about those formal mechanisms, among all the other kinds of communication we have seen take place in these spaces. Others have also mentioned using the complaints boxes, which stand in the clinic as well as in every section of the hospital. Xaks goes to interview the quality assurance manager at the hospital, about the complaint box system.

QA MANAGER: We are a committee, it's formed by all the unit managers, and we are eight. We open [the complaints boxes] every Thursday at 8.30, as the committee. When we are opening, there are three categories: there is complaints, comments and compliments. We choose letters of one unit [category] and put it aside. When we open, we count how many complaints received from female medical [ward]... twenty... then we write down. The complaint that is at the front, is the shortage of doctors.

She also mentions that people with disabilities are writing about the need for wheelchairs and crutches. The procedure for the boxes seems to be taken seriously, but the number of doctors remains the same, and the hospital still waits months for their assistive device orders to be delivered.

One of our participants tells us about a time she wrote a complaint for the clinic box.

MAMTHULI: I was saying [the clinic nurses] are working very hard, but they are too slow. The nurses were writing the list of people who were writing complaints, and putting it on the wall [at the clinic]. And they were explaining on that list, next to my name, the reason they are going slowly, it depends on the person they are seeing, how sick she is.

So the complaints receive a response. We are confused by her being identified by name with her complaint: did she write her name on the paper?

MAMTHULI: The message that you are writing on the paper, you didn't put your name, because they didn't want to know who it is coming from.

But it seems they do in any case. In a setting like this, it would not be difficult for staff to work out who wrote what. This cannot but have implications for people's willingness to raise complaints.

Has she seen any change as a result of her letter?

MAMTHULI: No, there is no progress. The problems are coming from the nurse, that's why they are slow. Except when they want to go to lunch, then they rush and go quickly. It's difficult to go to the clinic for the whole day, just waiting on the chairs for the whole day, not doing anything. They [the nurses] were calling their friends, receiving their calls, sending their SMS's⁹⁹, they don't care about the patient.

If this is indeed their attitude to the people coming for help, it is unlikely that a complaint coming from this group will change things. The complaints boxes seem like another instance of letting the calf go to the cow: again, healthcare workers are appearing to do their jobs, but not actually achieving their intent.

Of course, in many instances, there is not much the staff who receive such complaints can actually do about these issues. To hire extra doctors at the hospital would require not only willing applicants for hard work in a rural backwater, but also the cooperation of the human resources machinery, which shares the characteristics of the rest of the system. Patient transport and ambulance availability, issues regularly raised by our participants, have been flagged so often that, at the time of writing this, the South African Human Rights Commission was holding hearings in the Eastern Cape about emergency medical transport. This was the culmination of two years of concerted effort by a large chunk of civil society, under the banner of Eastern Cape Health Crisis Action Coalition. Fronted by some of the most skilled and successful advocacy organisations in the country, even this group had struggled to gain any satisfaction from the provincial Department of Health. The paralysis seems systemic.

It is no wonder then, that Xaks tells me the clinic committee in Kwabisi is "finished". Laying aside the issue of who represents the community in such bodies (I remember Nontombi's story and the shadowy Mr Q), what tasks would they actually take on? When the most concerning issues - waiting times, transport and drug availability - continue to go unaddressed, what is the point of continuing to meet?

I also question how people choose the issues they will raise. Xaks asks Sibongile if he has mentioned to the healthcare workers he sees for his ferrules that the black ones are preferable to the grey.

SIBONGILE: No, I didn't do that. I didn't remember [*it didn't occur to me*] that I can advise them on this.

If he simply didn't think of it, it would say something about how people (consciously or unconsciously) select the needs they express. It's possible though that as someone careful to "follow the right channels", he didn't feel he had a right to raise this. He said elsewhere:

SIBONGILE: it is difficult to make a difference because I'm not working in the health department.

It was also true that the nurses would have struggled, as I did, to find out how to influence the type of ferrule ordered.

⁹⁹ SMS: text message

Sibongile's story helped me to understand the complexities and risks around standing up for one's rights in this setting. Although he appeared to be doing exactly what a Western rights activist would have recommended, in reality he avoided being either oppositional or demanding. Both are potentially characteristic of the mainstream rights approach, and possibly the reason for its lack of purchase here, with both healthcare workers and villagers.

This finding pointed to something beyond a fear of confrontation and an authoritarian system. Through all of the stories, the underlying world view of the villagers was being surfaced. The value on hospitality, social harmony, and maintaining one's "dig" in the eyes of one's neighbours, seemed closely aligned with the common view of traditional African culture as strongly community-focused and deeply invested in relationships. At the same time, I was well aware that these things were rooted in a larger belief system or cosmology that also informed how people managed their health, in ways that I had not yet begun to understand.

The story that opened these things up for me was that of Thembinkosi, a young man with epilepsy and a hemiplegia, living alone in the location. While the health service featured very little, this narrative opened up a different way of looking at the entire social fabric within which the engagement between our participants and healthcare workers took place.

4.1.5. Thembinkosi: not what it seems

Thembinkosi is a young man in his early thirties, living alone in the family homestead – which is the first thing that strikes me as strange, in this society where hardly anyone lives alone. His parents are deceased, and he seems to have only one brother who sometimes stays with him (another is working in Johannesburg). He developed hemiplegia (weakness of one side of his body) in early childhood, apparently due to a series of severe fits. There is something deserted about the homestead when we go to visit, perhaps because the maintenance of the handful of buildings falls on one person, and they are obviously run down.

As he tells us his story, my ears prick up at this:

THEMBINKOSI: There are two people who did explain to me about the sickness...The one say you can be healed easily, but you are just two in your household, the other family members cannot help you.

I know that being with others is important in this community: *Umntu ngumntu ngabantu*¹⁰⁰, a person is a person through other people, as we have been told many times. The sense of abandonment is tangible here, and I wonder if this statement hints at a perceived connection between his impairment and his isolation.

I try to follow up on this comment in subsequent interviews, but the answer I want eludes me. I have already discovered how difficult it is to get people to express the underlying world view that informs their choices and interpretations – particularly to a white person.

It begins with the account of when he first became ill, when he was five years old. He tells it like this:

THEMBINKOSI: I was called in from another house by my mother, while I was playing with two black birds. Then when I dropped one of the birds, I started fits and I was paralyzed. I had fits

¹⁰⁰ The African philosophy of *Ubuntu*

from nine in the morning till midnight. And my mother took me to a *sangoma*, who tried everything without success.

I am completely confused. But later when Xaks and I discuss it, his response is the opposite: this makes perfect sense.

XAKS: The thing that was shocking me, was the time that he was carrying those black birds. *Wakungeka*¹⁰¹ – he was cursed by them... It's true, it's witchcraft. That is the way of witchcraft. The other boys were catching those birds, then no-one wanted to take them, but he took both and was putting them here [under his arms], and then he was starting to be ill. And after that, his mom took him to the *sangoma*. It seems his mother was right to take him there, because of this witchcraft issue.

KATE: Who was doing the witchcraft?

XAKS: Someone put a curse on the birds and knew he would pick them up.

KATE: But who wants to curse a five-year-old?

XAKS: They don't mind, if they want to use it, how old you are. It makes sense, the thing of starting to fit.

It goes further: Thembinkosi reveals in this interview that he has a "soft head". This means he is more easily affected by bad spirits and witchcraft than other people, and it is because he is not protected by the ancestors.

Maybe it doesn't come across in the text, but I was annoyed. I considered Xaks informed, enlightened, and yet he gave credence to what I saw as nonsensical superstitions. My reply brushed his explanation aside:

KATE: But fitting can be caused by a lot of things. A small bleed in the brain, maybe worms¹⁰² - anything might have led to a brain lesion that caused him to fit.

XAKS: [*nervous giggle*] I am happy to hear that. I don't have the words and maybe that is what I was thinking.

He is embarrassed by my tone; he knows exactly what I am thinking. Now I'm ashamed of myself, the "scientific" arrogance. I backtrack, and ask him to say more.

XAKS: It matches other stories I have heard. But the one thing I don't understand is the thing [he told us] of becoming a *sangoma* – that he had visions, of the house, the headscarf, the beads, the chicken. He brought those things together, and then he started training¹⁰³. What I

¹⁰¹ Literally "He was cursed". Xaks uses the Xhosa word here, to allude to a Xhosa reality. "Xhosa things" are not often spoken about with white people – my reactions in this story demonstrate why.

¹⁰² I'm referring to pork tapeworm. The eggs lie dormant in the soil, may be ingested via unwashed hands, and the hatched worms migrate to the brain and form cysts (neurocysticercosis). This is an extremely common cause of epilepsy in the region.

¹⁰³ The Xhosa term for the process of becoming a *sangoma* is *ukuthwasa*. It includes not only the formal training, usually several months to a year or more under the instruction of a senior *sangoma* (usually living in the teacher's homestead), but also the preceding process of receiving the call from one's ancestors to become a healer. This is characterised by disturbing dreams (often featuring key symbols or messages, like those

don't understand is how you can be training while you are sick. And then I asked him if he believes in traditional herbs, he said yes, but he is also taking the pills from the clinic. I asked if they are helping him and he can't say they are.

KATE: I'm trying to work out what you find strange. *Ukuthwasa* while you have a disability, fitting, continuing to take pills even though they don't seem to work – they all sound familiar to me. What doesn't make sense to you?

XAKS: It is the first time I hear of someone who is disabled who still goes to training.

KATE: But I know a lot of people with mental illness who go and train, or are interested to do it. Maybe that's because I see a lot of sick and disabled people in the hospital.

XAKS: It's the first time for me.

I'm not sure why I reacted so strongly to this story, why I was so determined to assert my own explanation for Thembinkosi's illness. Perhaps after years in a biomedical system, this was a knee-jerk reaction. Superstitions cause stigma and discrimination, we believe. If people can just understand that the cause is merely medical, scientifically explainable, this will all go away.

But it went deeper than that. When Xaks raised his own questions, I wanted to discount the strangeness of what he noticed. I suspect my resistance was actually to the feeling of being entirely in the dark, of having absolutely no understanding of what we were looking at. And it wouldn't go away.

So we returned to the theme of his social isolation, and I began to see again and again how this rendered him vulnerable. He starts a *spaza*¹⁰⁴ shop, but it is broken into by "friends" who have been spending time with him there. His money and stock are stolen. He is physically unable to pursue them, but when he later confronts them, they threaten to kill him if he reports them to the police.

On another occasion, he tells us:

THEMBINKOSI: I have to eat bread because I fear for my safety. If I could start cooking and be attacked by fits, then I can burn alive and the house will burn down. It is my brother who lights a fire when he is around, not me.

Xaks is confused by this: why won't he light a fire? I explain about flashing lights triggering fits, and how many parents of children with epilepsy will not let them come near a fire or go to the river. He has heard of this, but they forget about it after a while, he says. I disagree. As previously, Xaks has raised a question about this situation, and I have pushed it away.

I pursue the statement about why he could be cured if he had more family around him, and this is eventually pinned down to mere finances. If he had enough relatives who would lend him money, he could raise the considerable sum asked by a traditional healer to perform the ceremony. But he wasn't persuaded this healer could really help him. He suspects the man was just after his money.

I start to see it as a simple illustration of the importance of social support in a poor community, particularly for someone with a disability. I write his situation off as "bad luck": the unfortunate coincidence of a common illness with the early loss of his parents and an unusually small number of

Thembinkosi described), and often experiences of illness and personal setbacks. The belief is that if one refuses the call, the suffering and bad luck will increase and may even result in death. Going to train under a *sangoma*, with its attendant rituals, is seen as the only way to regain health and well-being.

¹⁰⁴ Spaza: small informal tuckshop, usually run from home, selling necessities such as bread, long-life milk, tobacco, candles and washing powder.

siblings. Nonetheless, I'm aware of the undercurrent of emotion about his isolation. He returns to this theme:

THEMBINKOSI: I like to stay with someone, because I have a problem of fitting. So I am afraid when I am staying alone, because one day I can fit and touch the candle, it's then I can end up burnt, or someone can enter the following day, and find me dry¹⁰⁵ in the house... I don't mind what person it is who stays with me, just someone who is going to knock and look that I am still alive.

It is perhaps significant that there is more than one understanding of "bad luck" between us. For me, it is pure chance – unfortunate but essentially meaningless. For him, and for Xaks, his "bad luck" means something much more sinister.

Here is what happens next. On a visit to Kwabisi, Xaks is passing Thembinkosi's home, when a neighbour calls him over, and asks him to go in and check on the young man. He suspects something is wrong. On entering Thembinkosi's room, Xaks finds him alone, bed-bound and delirious. He has been burnt over both legs and parts of his body, and for several days has lain alone without food, water or medical care. He is septic, soiled and in excruciating pain. Xaks asks help from some young men to carry him to his car, and takes him to the clinic. The nurses call the ambulance and he is admitted at the hospital in town.

With an irony that is almost malignant, it emerges that Thembinkosi had attended a funeral, and spent the night in the yard with the other men¹⁰⁶. The weather was cold, and against his usual precautions, he stayed close to the fire to keep warm. At some point, the others moved off, and left alone, he had a seizure and fell into the flames. When his companions found him, they took him home and left him in his house. Even more disturbing for me, the young men who helped Xaks, required bribing with beers to assist with moving him.

There are so many levels of cruelty to this. That after all his precautions, what he feared still took place. That when participating in a community event, he was still "struck down" alone, and that even with the presence of others, there was little help for him. And to me, that in spite of his vulnerability, those around him seem completely unconcerned, begrudging with their help. This is not the close-knit, supportive community usually associated with traditional African culture.

But Xaks' doubts finally come to a head, and he voices the suspicion that there is something "wrong" about this family. He can't pin down a cause, no-one has told him anything, but there is a social exclusion here that is not simply circumstantial. Another story:

THEMBINKOSI: I don't like to disturb people to ask for help, because my sister was deceased in Johannesburg, and I was telling the [extended] family and no one was helping me. So I end up burying her in Johannesburg... And in 2010, when my mother died, no one was coming to help me. So I am fed up to follow up with them. So I decide to forget about them, to do my own things.

¹⁰⁵ "Dry" meaning dead for some time

¹⁰⁶ Customarily, friends, neighbours and family members will stay over at the homestead of the deceased the night before the burial. The men will usually sleep in the kraal, a space with strong connections to the ancestors and off-limits to women at all times.

Xaks explains to me the implications of the Johannesburg burial: it will anger the ancestors, because the body of a family member must be buried at her home. Even if the body is buried elsewhere, the spirit must be brought home, a series of ceremonies including drawing the spirit with a branch from a particular tree, carrying it home (in a private car, because only the family members must be there), and a slaughtering of goats at either end of the journey. Similarly, the small funeral of his mother will only add to the ancestors' wrath. I don't understand why the relatives have refused him help.

XAKS: He was telling the family [about the death], and they said, we can't go there when *apha akonekuni lokubethainja*: there is not even the stick for hitting the dog¹⁰⁷...they refused to come because they said he has nothing, and he will just ask them for money.

KATE: Did they not respect his mother?

XAKS: In the rural areas, they do things according to the status of the house...they don't want to be associated with a small funeral, they would rather not be involved at all.

At first, I take this explanation at face value. I assume that this is a general rule, in a society that I find preoccupied with status. I have already seen the central role of funerals in maintaining and displaying social standing. I am surprised by how materialistic this supposedly community-oriented society seems to be. Ironical, I think, that Thembinkosi is poor because his relatives will not support him, and they will not support him because he is poor.

But I miss what Xaks is not saying here, because he takes it as given. Money is not separate from bad luck, curses, or social taboos: it embodies them. It carries meanings I don't see, is subject to unseen forces, and displays one's standing and power in matters that have nothing to do with material acquisitions. When Thembinkosi's relatives mock his poverty, they are both responding to and enacting something much deeper. Money is not "just" money.

I remember another irony in this whole transaction: the inadequate funerals of Thembinkosi's relatives will perpetuate and deepen the source of his misfortune, the anger of the ancestors. I can't capture this in a neat diagram with boxes and arrows any more. It's not a chain of separate causes and effects, it's more like a current, and it cannot be reduced to terms like "social support", "superstition" - or even "self-fulfilling prophecy". The balance tips, and I give up on finding "white" words to explain it.

I look for a piece of the thread to start with, a way in. There is his "soft head": not a chance characteristic, but an inherited lack of favour with the ancestors, embedded in his family's history and social identity. His epilepsy and his hemiplegia became a demonstration of this, and the visible manifestation must serve to reinforce his outcast status. Everything that happens to him because of his functional impairments - the burglary in his shop, the difficulties preparing food - might not be viewed by others with pity, but with a sense that the curse is justly being enacted. Although I'm still feeling my way in the dark here, I suspect that what prevents people from helping him is not fear that the bad luck might be contagious, but the perceived foolishness of challenging the actions of the ancestors, and perhaps the conviction that his situation is deserved.

The question arises: if one is under a curse of this kind, can anything be done? Thembinkosi's training as a *sangoma* made sense both to Xaks and to me now. *Ukuthwasa*, the process of training, includes elements to propitiate the ancestors, and a *sangoma's* powers could be used to counter the forces

¹⁰⁷ Expression to say the household is extremely poor, i.e. there will be no burial societies to pay out, no resources to contribute to the funeral

poised against him. We had been puzzled that he had never performed healing for clients from the location, even though he explained to us that he had become a *sangoma* to help himself and not others. He had described holding ceremonies with the other *sangomas* at his home, all-night dances that may have been intended to strengthen his defences. I had observed that perhaps this community had offered him an alternative source of “social support”, but again, it went deeper than what this English term could convey.

Thembinkosi also speaks of going to see a private doctor in town, when he has “power” (meaning money, which seems an appropriate transposition). There is nothing unusual about his use of both Western and traditional medicine: it’s mentioned by most of our participants, although some clearly favour one over the other. Thembinkosi seems to have little faith that the state healthcare system can help him:

THEMBINKOSI: I have always gone to doctors at the hospital. That is why I want to try a different doctor and see if there will be any difference in my health. Even my mother and younger brother were discharged from the hospital and sent home while still ill. And it was not long before they passed away. So I lost confidence in the doctors at the hospital.

INTERVIEWER: But do you still believe that your clinic medicine can help your sickness?

THEMBINKOSI: I am not sure because I continue to be sick even though I am taking the medicine.

INTERVIEWER: Why are you continuing to take it?

THEMBINKOSI: I am just being loyal to my treatment.

Like Nozukile, he continues to take pills even though he does not believe they are helping him. I don’t understand, although this may have something to do with it:

THEMBINKOSI: I am happy to go to the clinic. But one day, when I went for the treatment, the nurses chastised me severely for not coming to the clinic [before]. And they sent me to the doctor who did the same and from that time on, I have been to the clinic more often when I am sick. When I am due to go, I do go.

I wonder now what sickness he hoped the pills would help with. I assumed he was being given anti-epileptics, but like Nontombi’s daughter, he may never have been put on the correct dose. At the same time, perhaps he expected the medication to cure him entirely, including his hemiplegia. No wonder he felt it wasn’t working.

At another time, he says:

THEMBINKOSI: It is only me and my younger brother left, there is no other person left in the family, we do not have parents. And I do not have money. Other than that, I could have taken a wife to look after me.

Getting married in this society requires the payment of *lobola*, a bride price to the woman’s family, which can be a serious financial obstacle. I wonder a little about what woman would agree to marry him. She would have to be desperate to ally herself with this outcast family, most likely poor and of low social standing. Could a bond with such a person carry enough weight to counter the curse Thembinkosi is living under? Or would it be simply a matter of having someone to cook for him?

I had my answer: the health of one's body is, after all, essentially bound up with one's social relationships, with where one fits in the community and in the cosmos. The tablets and clinic visits seemed trivial, almost incidental to the nature of Thembinkosi's illness and disability. My highly Western attempts to pin him down to a neat explication of this, receive what they deserve – this essential truth reduced to small "practical" problems like access to finance and someone else to cook for him. Afterwards, reading over his evasions of my questions, I wonder if even I was forcing him into more disfavour, speaking about things that shouldn't be spoken of.

This is the hardest story to place within my research, because it says almost nothing about the primary healthcare system. But the complete disjuncture between the two worlds, the world of the clinic and the world of *sangomas* and black birds and ancestors, perhaps tells something in itself. I played my part perfectly, the Western healthcare worker dismissing things I don't understand as superstition, "not real", with scientific scorn. I got to observe, in retrospect, my own resistance to not knowing, and how this silenced the people around me.

My previous understanding of disability as a curse still placed the impairment itself at the centre of the picture. A child is born with cerebral palsy because the mother has done something to anger the ancestors. It was, in my understanding, a one-off event, cause and effect. What Thembinkosi's story revealed was a much bigger story, perhaps spanning generations, in which a disability like his was merely one more illustration, one more mechanism by which the curse was played out. And the curse was more specific than I'd understood: it was not general misfortune, but social death. In a society where nobody lives alone, you only exist in terms of those around you. People are of a piece, and as one person alone you are nothing, you cannot survive. The physical way in which this is also true in this setting, is not the main event, but only an echo of the underlying reality.

I also began to notice how every social interaction contained a great deal that was tacit. While I was focused on the questions of the research and the words people gave in response, they were focused on something else: what kind of a person is this? The overarching concern in every interaction was to demonstrate one's commitment to the social whole, and to establish whether the other was similarly oriented. The lengthy greetings, the long silences, the mistrust of directness, all pointed towards the need to show a value for "being together" over pursuing any kind of personal goal. I obviously failed this test consistently. Within the health service spaces, such patterns were discarded in favour of efficiency and the dominant medical approach. But as a backdrop, this focus on social coherence heightened the significance of a reciprocal and collaborative engagement between healthcare seeker and worker. Perhaps it even went as far as explaining Nozukile's miraculous healing.

Understanding how our participants saw the world also made more sense of their choices and actions. Phindile's story highlighted the role of family relations and community context in coping with challenges, including health. Nontombi's illustrated how a close-knit community could have negative effects as well as positive ones, and showed up some of the tensions beneath the surface of community participation in healthcare. I had found it extremely difficult to understand how a supposedly collective society could also engender the kind of cruelty experienced by Thembinkosi, and the intense jealousy often visited on a community member who achieved success, particularly in local business. Customary altruism, for example paying school fees for neighbours' children and sharing earnings with multiple relatives, was explained in that if everyone was not separate but of a piece, doing good to others was the same as doing good to oneself. A darker corollary however, was

that others' success could only happen through their taking from you, and so someone who succeeded financially was seen almost as a thief¹⁰⁸.

All this served to highlight how much might be missed by healthcare workers (particularly cultural outsiders such as myself). As to what it might mean for how services are provided, there were no clear answers, except that human interactions needed to be considered far more seriously as an essential dimension of care, and assumptions about "the community" held lightly.

¹⁰⁸ This was particularly marked for people who ran small businesses in the location, where customers were also one's neighbours. In spite of the logic of providing a service or goods for which people should pay, it seemed that the visible handing over of one's cash to a neighbour, reinforced the idea that he or she was becoming rich by taking from others. The practice of buying on credit and settling accounts on pension pay-out day, also served to separate the benefit from the payment, possibly reinforcing the effect. Thembinkosi's experience of having his spaza robbed by "friends" was by no means an unusual occurrence, and there was reportedly a widespread practice of paying a *sangoma* to curse someone who was seen to become too successful. Accidents and illnesses were often attributed to witchcraft, and it is possible that the episode with the black birds was interpreted by the family to be related to some feud or conflict.

Part 2: Characterising engagement

The five stories in Part 1 addressed the first two objectives of the study, namely to describe the participatory spaces in which rural people with disabilities engaged with PHC workers, and the ways this engagement played out through the occupations of both groups. The stories captured ethnographically how people's actions and interactions were shaped by their respective life contexts and by the immediate situation in which they found themselves.

Part 2 addresses the third study objective by providing a thematic interpretation of the engagement of rural people with disabilities with healthcare services, based on all eleven cases studied. Table 10 summarises the three themes emerging, with their respective categories and subcategories. **Theme 1, Immersive life fabric** captures the lifeworld of participants, which created the context for arising health needs and framed the process of healthcare seeking. **Theme 2, Quiet autonomy** presents the array of strategies and stances adopted by people with disabilities as they negotiate lifeworld and health system spaces to address health needs. **Theme 3, Contradictory spaces**, describes the dynamics of the health system space, and two contrasting approaches adopted by healthcare workers in this context.

Together, the three themes describe how interlocking spaces and approaches to engagement could result in an overarching plot of **capability suck**, or conspire to achieve **capability release** in the life context of people with disabilities.

Table 10: Characterising engagement: thematic description

Theme	Category	Subcategory
1. Immersive life fabric	Physical survival	On the periphery
		Physical livelihoods
		Physically vulnerable
		Public private life
	Social survival	Keeping your "dig"(nity)
		Connecting to the whole
	Connected for better or worse	Practical interdependence
		Compacted social spaces
2. Quiet autonomy	Strategizing for engagement	Weighing options
		Mobilising opportunities
	Approaching engagement	Presentation as invitation
		Waiting to be asked
		Evaluative gaze
		Owning one's body
		Challenging carefully
		Silent resistance
3. Contradictory spaces	System tensions	Rhetoric vs reality
		Unresourced imperatives
		Caught between
		Encapsulated encounters
	Futile reproduction	Reductive gaze
		Formulaic interventions
		Silencing

	Collaborating to heal	Willing to greet
		Doing their best
		Helping each other

4.2.1. Theme 1: Immersive life fabric

This theme described the context in which participants lived their lives, and the ways in which this context shaped their daily occupations and concerns. The rurality of the village contributed certain characteristics to the physical and socio-economic space, which interacted with Xhosa cultural values and world view. Together these factors created a social dynamic that could both lend strength and coherence to people's lives, and constitute a threat and constraint. The deep connections between physical and social survival, most vividly portrayed in the story of Thembinkosi, shaped the occupations and choices of all of our participants, including their engagement in healthcare seeking.

Three categories emerged. "Physical survival" comprised four sub-categories describing the physical nature and demands of livelihood in this setting. "Social survival" comprised two sub-categories that captured the ways in which people maintained their position in the community and in the cosmos as they saw it. "Connected for better or worse" included two sub-categories describing how survival demands and socio-cultural norms interacted to bind community members to one another, with both positive and negative implications.

4.2.1.1. Physical survival

a) *On the periphery*

The sense of physical and social distance from the opportunities and activities of society was pervasive. It not only increased the costs of accessing opportunities such as healthcare and trade, but it reduced access to knowledge about these things, so that opportunities might be missed or efforts wasted. Several participants also felt that the healthcare, products and other services available to them were of poorer quality than those elsewhere. This related not only to the rural district where they lived, but also to the province, which was widely seen to suffer from inefficient, corrupt and ineffective administration.

b) *Physical livelihoods*

Daily occupations were characterised by intense physical demands, from carrying water to building and repairing homes. Travel was often on foot, which posed a considerable barrier even to attending local events such as tribal meetings and funerals. The time required for all of these things, particularly for people with mobility impairments, was a major limitation on people's occupational possibilities.

c) *Physically vulnerability*

Physical vulnerability was experienced by both disabled and non-disabled villagers, although the former could be at greater risk for violence and crime. This was due not only to their physical or mental limitations, but also to the amount of time they took to move around the community, sometimes resulting in night-time travel. The monthly pension pay-out was a time of particular risk, as grant recipients would be known to have cash on hand, and were sometimes robbed en route or in their homes. There was no police presence in the area due to the distance from town.

The type of dwellings in which people lived and the lack of infrastructure, meant that much of life was lived outdoors. The rainy season often brought big storms, and homes could be badly damaged or even struck by lightning. Winters could be extremely cold, sometimes with snow. While all community

members experienced this risk, people with disabilities might have more difficulty repairing homes or coping with exposure.

d) Public private life

Another function of the physical layout of the community was the lack of privacy with which people had to conduct their lives. Within the household, most space was shared, and seldom did anyone have their own private space. Cooking, laundry and washing was usually done outdoors, and activities in the yard would be visible to all passers-by, as homesteads were usually wire-fenced, if boundaried at all. According to local custom, it was a matter of family pride for one's door always to be open for one's neighbours, and people visited one another at any time of day. Suspected attempts at privacy or secrecy were considered suspicious, as was any inclination to spend time or do things on one's own¹⁰⁹.

4.2.1.2. Social survival

(a) Keeping your "dig"

The importance of maintaining the dignity of one's household and oneself, in the eyes of the community, pervaded most activities. The above categories explain to some extent why this was so, in ways that were possibly different from less close-knit and circumscribed social settings. "Dig" represented social status, and could be affected by material wealth, prestigious connections, and being seen to behave rightly. Right behaviour included wisdom and prudence in personal affairs, as well as being seen to honour and affirm social harmony, order and solidarity.

(b) Commitment to the whole

Closely linked to maintaining one's social standing was the necessity of continually demonstrating one's respect for relationships, attention to social harmony and commitment to the community over oneself. This included social practices such as greetings, patterns of verbal and non-verbal communication, respect for hierarchies and "the proper channels", as well as more fundamental choices about how time and resources are spent. Observing customs and rituals such as initiation, funerals and traditional marriage, was critical, especially as the social whole was seen to include not only the living but also the ancestors. Failure to honour these obligations would result in cosmological rupture, with the ancestors' displeasure potentially resulting in material, physical, psychological and spiritual harm.

4.2.1.3. Connected, for better or worse

a) Practical interdependence

The context of poverty and physical demands of survival in this underserved community meant that people depended upon one another to share scarce resources of finance, goods in kind, labour and protection. Households were generally economic as well as social units, and the cost of seeking healthcare affected the whole household materially and practically, as did the presence of a member with a disability in many other matters (including the positive impact of the disability grant). People

¹⁰⁹ My appearance in the community, leaving my family in Cape Town, was in itself considered fundamentally inexplicable, as were my various solitary activities during my free time, including reading alone in my room and going running or cycling in the community. All of these were observed and commented upon with interest, being clearly not considered 'personal' matters.

with physical or mental disabilities often needed a great deal of practical assistance and support, for example to move about in a wheelchair or collect water and fuel.

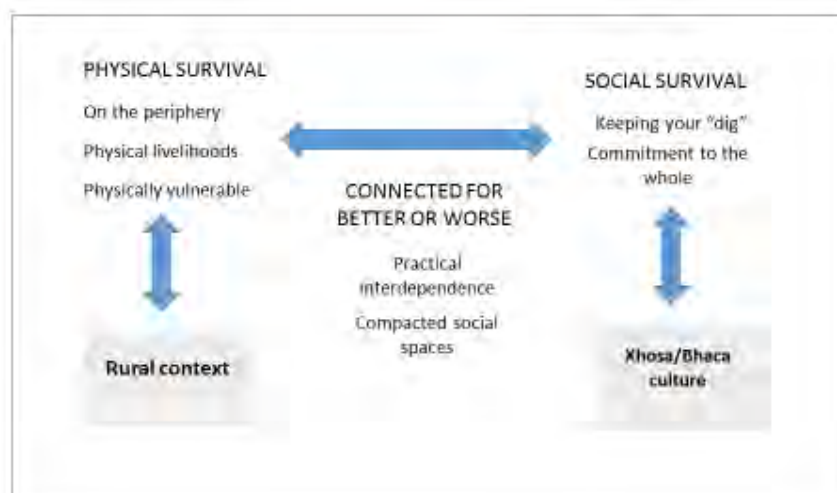
(b) Compacted social spaces

The social structure and small size of the community meant that one constantly encountered one's neighbours, on public transport, in clinic waiting rooms, at social events and in most other activities. People held multiple roles in relation to one another, including neighbour, relative, fellow member of *umgalelo* or burial society, and creditor. This meant that relationships with others in each space needed to be tended carefully, as disruption in one setting could have far-reaching ramifications.

Physical and socio-economic realities intersected with socio-cultural norms to create complex patterns of interdependence that bound people to one another. This was the overarching plot of interwoven physical and social survival that characterised the **immersive life fabric** of our participants. Social belonging and connection was considered the essence of being, and was also the basis for physical survival. At the same time, the underlying sense of connectedness could carry a risk, at times preventing people from acting in ways that might have been more beneficial for themselves or their families, but which might be considered suspicious by others. This was especially evident in small businesses, where success could be regarded with jealousy and suspicion. Being perceived as a threat to the social whole could result in hostility and exclusion, which was materially as well as socially dangerous.

Figure 5 portrays the above categories in relation to each other, demonstrating the ways in which physical, socio-economic, and cultural dimensions of the rural community space interacted to shape people's choices and occupations.

Figure 5: Immersive life fabric



4.2.2. Theme 2: Quiet autonomy

Occupations of healthcare seeking were captured by the theme **Quiet Autonomy**, which comprised two contrasting categories: **Strategising for engagement** and **Approaching engagement**. The first category described the occupations through which participants planned and leveraged opportunities and resources to seek healthcare. The second category described the strategies they adopted once within the participatory spaces where healthcare itself was negotiated. A paradox was evident between the two: while the former was characterised by considerable creativity and often great effort and expenditure of resources, the latter was characterised by caution, hesitance and apparent inaction.

4.2.2.1. Strategizing for engagement

Nested within the broader setting of Theme 1, this category described how participants made decisions about accessing healthcare, and mobilised opportunities and resources to make this possible. These occupations were characterised by variety, creativity, and complex reasoning about their situations. Most took place out of sight of healthcare workers, but formed the backdrop for participants' actions and interactions within the participatory space. The process of strategizing took into account the broader occupational demands, priorities and processes described in Theme 1, as well as the specifics of healthcare seeking occupations and needs.

Health needs interacted with daily occupations of social and physical survival, either disrupting these, arising from them, or both. Healthcare seeking offered the potential to expand, restore or secure capabilities lost or threatened due to the health need. However, it also drew resources from other occupations, and could compromise or sacrifice existing capabilities.

(a) Weighing options

Participants considered the costs and feasibility of seeking healthcare, against their need for it, and their assessment of which sources are likely to be helpful. This reasoning process had to take account of the household needs and situation, previous experiences and relative faith in healthcare providers, among other things.

(b) Mobilising opportunities

Participants showed ingenuity and creativity in applying the resources they had, to make it possible for them to seek healthcare. There was a surprising range of strategies described, from keeping airtime on one's phone so as to be able to contact a neighbour, who would then call a relative to come and help (Nozukile), to negotiating credit with taxi drivers for a trip when one had no money to pay fares (Sibongile). They also tried a range of healthcare sources, including local traditional healers of various kinds, retail pharmacies in town, leftover medications from family members, as well as mainstream health services.

There was an ongoing cycle of weighing options and mobilising opportunities. Following each encounter with health services, the participants would reconsider their position, weigh up what had happened, and then decide what to do next, in the light of the broader situation. The whole process was contingent on a wide range of factors, but also characterised by a sense of agency and autonomy in addressing personal and household needs and goals, within the constraints of the opportunity structure.

4.2.2.2. Approaching engagement

This category described how people with disabilities approached encounters with healthcare workers. It was characterised by an explicit level of interaction which followed the understood rules for health service spaces, generally with apparent compliance and submission, and a tacit level of expectation

and evaluation of the healthcare workers' response. The occupational strategies adopted by participants in the encounter were shaped by the relational environment created by the healthcare worker.

(a) Presentation as invitation

Participants offered healthcare workers descriptions of their symptoms, their bodies for examination, and other sources of information such as letters of referral and clinic books. These acts followed a familiar script guiding the role expected of the patient, and were clearly shared by our participants and shaped by previous experiences with healthcare workers. This presentation formed an implied invitation for the healthcare worker to engage, and coexisted with a tacit expectation of how they should do so.

(b) Waiting to be asked

Participants deferred to the healthcare workers' leading in the interaction, waiting to be asked for more information rather than volunteering it, and generally not intervening actively, even when the healthcare worker did not do as they hoped or expected.

(c) Evaluative gaze

The most active element of their engagement was almost entirely tacit, i.e. the observation and judging of healthcare workers' actions against their expectations of how the doctor or nurse should proceed (e.g. ask further questions, use the stethoscope, take bloods). This evaluative gaze was based on both beliefs and knowledge about healthcare interventions, and incorporated both an assessment of clinical skill or effectiveness, and a judgment on the healthcare worker as a person. The latter concerned mostly how the healthcare worker related to others, including caring and respect. Together these judgments informed satisfaction with the encounter, and what the participant chose to do next (i.e. fed into **Weighing options**)

(d) Owning one's body

Although the first three sub-categories described a quiet and apparently submissive approach to the encounter, participants were clear about their essential right to make decisions about their own bodies, and to refuse treatment if they so wished. Several told stories about resisting a doctor's recommendation for surgery, and one reported that the doctor in question refused to help him further because he had turned down the procedure. There was a strong sense that the knowledge one held about one's own body was invaluable for its treatment, although this was not always recognised by healthcare workers.

(e) Challenging carefully

Participants used the complaints box mechanism to raise concerns about waiting times, staffing and ambulance services. They included compliments as well as criticisms. No-one reported change as a result of their complaints, and when the response was negative or indifferent, they did not pursue the issue. Sibongile was the only one who described actively claiming his rights as a disabled person, but had to do so with great care and skill in avoiding direct confrontation. He succeeded by nurturing consensus, using shared reference points and finding indirect ways to assert his rights (e.g. letting the nurse see him reading the notice on the wall).

(f) Silent resistance

In place of direct confrontation or refusal, participants were more likely to adopt a show of compliance, while resisting in actuality. Participants might agree to a healthcare worker's instructions during the encounter, but take other action once this was over, while others chose to disengage from the health service entirely.

Tacit rather than explicit resistance seemed to be shaped from two directions. First was the power dynamic between participants and healthcare workers, which produced negative consequences to non-compliance, and constrained what people with disabilities were able to do. Secondly, the culture of this community placed great value on social harmony and consensus, hospitality, respect for hierarchy, and mutual respect and regard. This made open/explicit conflict unacceptable, even where power relations between individuals might otherwise make this seem possible.

Silent resistance as a strategy was also reflected in relations between community members, where a person or household wished to preserve their autonomy and privacy. Nontombi was an example of how a vulnerable person (by virtue of her gender, socio-economic position, education and social status) preserved her autonomy in the face of attempted influence by community leaders and neighbours. We also experienced this in our interactions with some of our participants, who while apparently welcoming us, politely withheld the information we asked for.

4.2.3. Theme 3: Contradictory spaces

This theme described the nature of the participatory spaces within which healthcare workers encountered rural people with disabilities (in the category **System tensions**), and the two types of engagement they chose within this context, namely **Futile reproduction** and **Collaborating to heal**. While these took place predominantly in the physical spaces of the health service (e.g. clinic and hospital), they also included interactions in the community, for example during home visits by *nomakhayas*.

4.2.3.1. System tensions

The participatory spaces were characterised by dissonance between the voiced intentions of policy and healthcare worker actions, and the realities of the service and surrounding context. These tensions between the ideal and the real, the expressed and the tacit, shaped healthcare workers' occupations, and in turn the engagement between healthcare workers and healthcare seekers.

(a) Rhetoric vs reality

Sometimes visible signs of official policy and rhetoric contrasted ironically with other aspects of the space. One example was the clinic book in Nozukile's story, intended as a tool for healthcare seeker empowerment and continuity of care, but failing to achieve either. Another was the waiting room scene observed when we visited the hospital with Phindile, where posters on health rights contrasted powerfully with the under-resourced service and the hierarchical interactions with healthcare workers. What was particularly significant was that these contradictions seemed to go unchallenged by healthcare seekers, and largely unnoticed by healthcare workers.

(b) Unresourced imperatives

The paradoxes in the category **System tensions** were often created by the absence of appropriate resources to carry out the intentions expressed. From healthcare officials senior to the frontline healthcare workers came both the failure to provide these resources, and the insistence that certain activities were performed regardless. This placed healthcare workers in the position of needing to adapt such performances to fit the constraints of the setting, resulting in occupations that might seem contradictory or obviously ineffectual. This was an important contributor to the strategies described in **Futile reproduction**.

(c) Caught between

Healthcare workers often experienced conflicting demands, operating in tension between the directives of their superiors and the needs of their patients. The previous two subcategories created conditions that meant people's healthcare expectations often went unmet, and frontline workers could be blamed by community members for service failures outside their control. At the same time, a distant and unsupportive management structure produced a sense of isolation and frustration, as healthcare workers' reports and complaints about lack of resources and poor working conditions generally went unheeded.

(d) Encapsulated encounters

The final subcategory describing the participatory space was about the 'encapsulated' nature of each healthcare encounter, in terms of both space and time. Time-wise, the system made little allowance for continuity of care, and healthcare seekers seldom saw the same doctor twice. This had implications not only for the treatment relationship, but also in the motivation for the healthcare worker to engage actively in the process.

In terms of space, both physical and socio-cultural, health services were separated from the context in which healthcare seekers lived. While community and clinic level healthcare workers were more in contact with this reality, most significant treatment decisions were made at the district hospital, which was almost entirely removed from it. Healthcare workers were observed, as a result, to make assumptions about people's lives and capabilities, which informed assessments and treatment decisions not necessarily appropriate to the situation.

4.2.3.2. Futile Reproduction

This category described one set of occupational strategies adopted by healthcare workers to cope with the pressures and contradictions of **System tensions**. While this way of being and doing as healthcare workers was by no means universal, it recurred across many of the stories we heard.

(a) Reductive gaze

Assessments and observations of healthcare seekers were cursory and quick to reach conclusions, often based on assumptions rather than detailed information, particularly about the life context of the person seeking healthcare. Linear explanations were used to attribute an illness or behaviour to a single cause, without testing alternatives. Phindile's diagnosis of "substance-induced psychosis" was one such example. Value judgments were made on healthcare seekers and their family members about their responsibility for a situation, and the morality of their behaviour, based on preconceived ideas about healthcare seekers and specifically people with disabilities and their families (e.g. Nontombi's judgment by the *nomakhayas* for failing to take her daughter to the clinic). Judgments were also applied to the importance of an illness, based on biomedical frameworks and priority conditions identified by the health system, rather than on their impact on the person.

(b) Formulaic interventions

The processes described in the first three categories led to prescriptions or actions which were repeated without reference to whether they worked or not. They tend to be delivered in isolation, as the single response to the presenting difficulty.

These strategies tended to be repeated over time, creating cycles of futile engagement. Healthcare workers might simply repeat what the previous clinician had prescribed or diagnosed, without considering whether this was appropriate. Formal protocols and accustomed procedures might be repeated in similar ways, creating 'procedural loops' shunting a patient from one service to another,

without consideration for whether this addressed the problem. Phindile's story stood out for how this was seen to occur across the system.

(c) Silencing

Healthcare workers tended to curtail engagement by either actively silencing healthcare seekers with disapproval or hostility, or by refusing to engage in further questioning, a physical examination, or reading documents. Silencing worked in concert with the reductive gaze, and value judgments could be either a motivation for or a means of silencing. Healthcare workers exercised their power in the participatory space to reduce the time and effort expended in each encounter. High workloads and understaffing certainly created the pressure to work quickly, but the ineffectiveness of this set of strategies often meant healthcare seekers simply came back again.

The category of **Futile reproduction** described a "going through the motions", or "letting the calf go to the cow". The heavy cost for our participants in repeat visits and prolonged illness and suffering seemed unnoticed by healthcare workers, but was vividly apparent as we followed their stories over time.

4.2.3.3. Collaborating to heal

The third category in this theme described a second and contrasting mode of engagement by healthcare workers, represented mostly in our participants' descriptions of their ideal of care, as shared engagement in addressing the health problem, within a relationship of respect and reciprocity.

(a) Willing to greet

Courtesy and friendliness were valued in healthcare workers, both inside and outside the clinical encounter. Greeting, a significant practice within the Xhosa culture, seemed to signify a human acknowledgment and engagement from a doctor or nurse, rather than an impersonal detachment from healthcare seekers, which was often the case.

(b) Doing their best

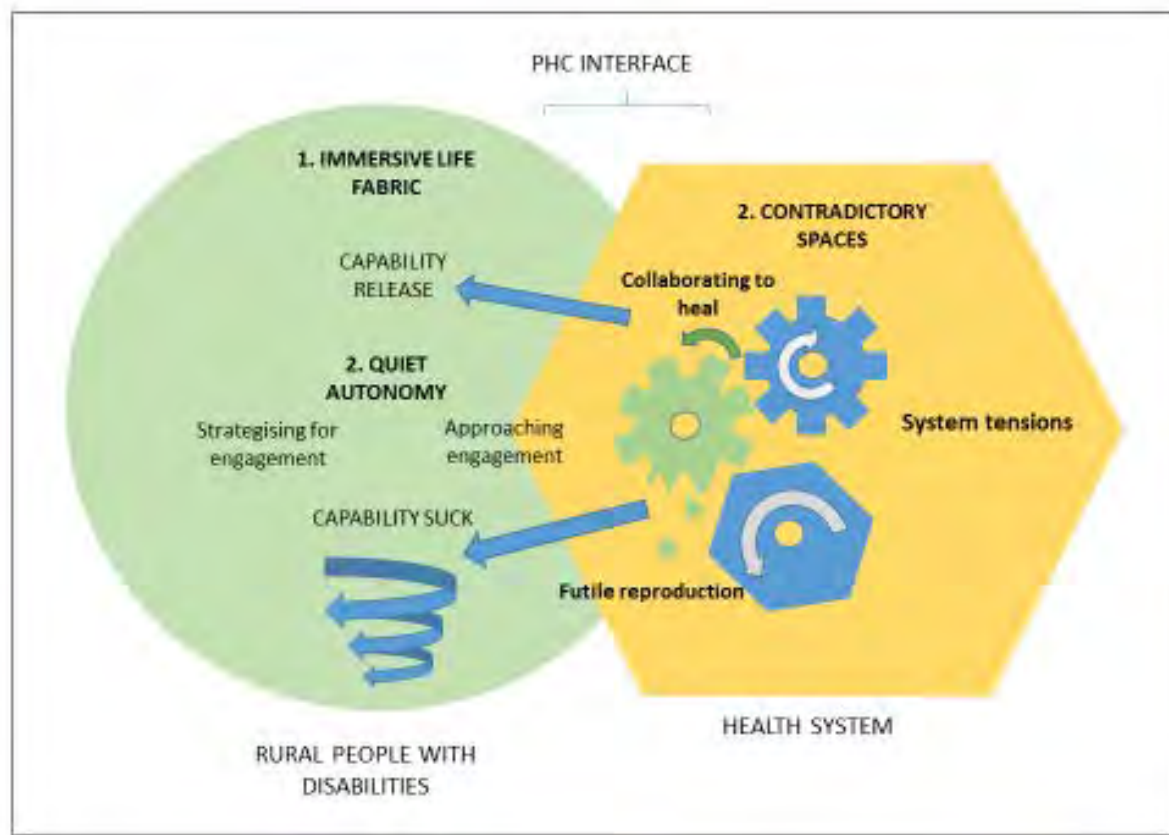
An identification with the concerns of the healthcare seeker was not taken for granted, and where a genuine willingness to help was perceived, even failed interventions could be experienced as satisfactory. While participants could not always judge the clinical appropriateness of an intervention, it mattered to them that the task of physical examination was carried out thoroughly, characterised by both taking time and showing attentiveness. Whereas **Futile Reproduction** was driven by a 'going through the motions', **Doing their best** included engaging with the particular needs of the individual, including practical concerns, which opened up the possibility of creative problem-solving within the constraints of the system.

(c) Helping each other

Participants placed value on their own knowledge about their bodies, and believed that wise healthcare workers would do the same. Healthcare workers' taking time to listen, and taking seriously the inputs of the healthcare seeker, were highly valued. Those who showed respect for the autonomy and expertise of healthcare seekers, were more readily trusted, and perceived as more effective clinicians. **Helping each other** was a joint engagement in the task of healthcare, and the reciprocal nature of the process was essential to the relationship and the outcome.

Figure 6 depicts the three themes as they related to each other, producing a trajectory (or plot) of **capability suck** or **capability release** for healthcare seekers. This is described in more detail below.

Figure 6: Mapping engagement: Capability Suck, Capability Release



The diagram depicts the life context of participants (**Immersive life fabric**) and the health system context (**Contradictory spaces**) as two overlapping forms, meeting at the PHC interface. The green circle on the left represents the former, while the orange hexagon on the right represents the health service. The area of overlap between the two forms represents the interface, where both contexts come to bear. The hexagon is foregrounded however, representing the dominance of health service processes and rules within the participatory spaces, to the exclusion of rural people with disabilities' life circumstances and concerns.

Quiet autonomy is seen to operate across both contexts, with its first category (**Strategising for engagement**) being located in the **immersive life fabric**, and the second (**Approaching engagement**), taking place within the health system.

The engagement between PHC workers and people with disabilities in the interface is depicted as a set of cogs, which must interlock and move together to produce a positive outcome. The green cog represents people with disabilities' **Approaching engagement**, while the two blue cogs represent two contrasting approaches adopted by healthcare workers. The lower cog (**Futile reproduction**) is hexagonal, lacking teeth to engage (literally) with the green cog, and their meeting produces an uncoordinated grinding, which fails to achieve its purpose and damages the green cog in the process. This mis-engagement can drive in a downward spiral of **Capability Suck**, which is invisible within the health service space but plays out in the **Immersive Life Fabric**.

The upper cog, representing **Collaborating to heal**, is shaped with teeth to interlock neatly with the green cog, allowing smooth, coordinated movement together. In this interaction, people with

disabilities and healthcare workers genuinely engage one another in a manner that fulfils the purpose of healthcare seeking. This kind of encounter produces health in the form of **capability release** in the life fabric of people with disabilities.

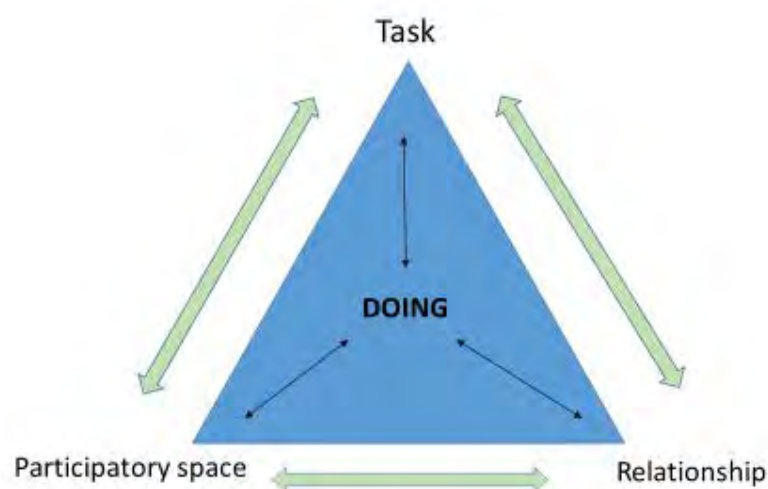
The trajectories of capability suck and release are be discussed further below. First however, we turn to the dynamics in the participatory space, to understand at a micro level how engagement is shaped.

4.3. The engagement triangle

I came to understand engagement in the participatory spaces of the interface in terms of interconnected task and relationship: not merely a process of communication but also shared action towards a particular goal. By exploring the interplay between the characteristics of the participatory space and the occupations of participants and healthcare workers, I also came to see how the setting shaped and constrained what was done, and the way in which it was carried out. This in turn influenced the relationship between actors, and their perceptions of the task or purpose of the encounter.

The interrelationships between these elements are depicted in Figure 7. Each of the three elements is seen as shaping what people actually do in the encounter, and the doing in turn shapes task, relationship and space in an ongoing, multidirectional dynamic, as the interaction unfolds. “Doing” refers to the enactment of the encounter, including each person’s words, actions, perceptions and internal processes. It includes the activities described in **Quiet Autonomy** (e.g. watching and waiting, evaluative gaze), and those in **Futile Reproduction** and **Collaborating to heal** (e.g. silencing, formulaic interventions, listening and respecting).

Figure 7: The engagement triangle



The interactions between the three dimensions were complex and multiple, varying across encounters, but the significance of the three dimensions working together was consistent. The following sections will explore each element in more detail, as well as their interactions with each other.

4.3.1. The task of the encounter

Task was understood as each actor's perception of the purpose of the encounter and her part within it, including the activities it should entail, and expectations of how each party should act. The term 'task' is used intentionally here to position the encounter within the hierarchy of roles, tasks and activities, described in the conceptual framework. The roles being played out included doctor, *nomakhaya* or nurse, as well as patient, parent, community representative or caregiver. The task of seeking healthcare might be undertaken as self-care, but could also be motivated by the need to fulfil roles such as breadwinner or head of household, which were being obstructed by a health need. Life endeavours such as running a successful business, caring for one's family or becoming educated, were the larger context within which healthcare seeking was enacted, and this shaped decisions made and evaluations of care received. A critical realisation was that healthcare seeking was not separate from the other occupations and endeavours of participants' lives, but interwoven with them in complex and often highly personal ways. This broader occupational context shaped when and how people interacted with healthcare services, and how they interpreted the experiences of doing so.

A healthcare worker's conception of the task of the encounter might or might not take account of this occupational reality. Tasks seemed often to be perceived in terms of disease protocols and symptom removal, rather than interpreted according to the healthcare seeker's broader situation. Task perceptions could also be shaped by perceived responsibilities to the institution, one's colleagues and other patients, and the need to balance these against each other. The demands of the service, including workload, short-staffing, resource constraints and managerial pressures, could also take precedence, rendering the task one of survival or adaptation in a difficult work environment, rather than effective care. These various 'pulls' often meant that the task of an encounter was perceived differently by the healthcare worker and seeker. Because the conception of task was largely tacit, this could result in confusion, suspicion and unmet expectations, when others did not act in line with the assumed task.

Ambiguities around the task of a healthcare encounter were of particular significance for chronic illness and disability. Acute disease or injury tended to indicate a more clear-cut path of action, especially when the allopathic diagnosis was clear and relatively familiar to both parties. By contrast, most of our participants had long-term impairments which were unlikely to be cured, and did not necessarily have a formal diagnosis. Expectations about what was possible through good medical care often needed to be negotiated, and some people made costly repeat visits to a variety of services, before they were satisfied that nothing more could be done. The almost complete absence of rehabilitation services, and the limited disability knowledge of PHC providers, were serious barriers to effective and satisfactory healthcare. The chronic management of conditions such as mental illness, pain and epilepsy, placed different demands on households to those imposed by more acute conditions, and the question of perceived value and sustainability of healthcare seeking was pivotal to continued engagement with services.

At a fundamental level, the conceptualisation of task turned on the understanding of health itself. Where this was narrowed to mean mainly treatment of disease and removal of symptoms, our participants' needs were often perceived as insignificant (either because of the diagnosis was not

considered a 'priority' condition, or because their conditions were not curable). This was often inherent in the reductive gaze of healthcare workers. Participants themselves evidently experienced their health needs as serious, in terms of the impact these had on daily life, and this was reflected in the time and resources they were prepared to invest in seeking help. In other instances, healthcare workers placed priority on a health need and its management (for example adhering to hypertensive medication), which was not shared by participants. For people with disabilities themselves, health seemed to be conceptualised in terms of participation in valued roles and endeavours in their households and communities, rather than in terms of impairments in body structures and functions. Seeking healthcare could enable participation when successful, but could also actively obstruct it, through the diversion of resources, loss of opportunities, and the social risks of entering the healthcare space, in certain circumstances.

4.3.2. The participatory space

The participatory space included not only the moment of encounter and opportunity, but also the broader context for the visit: the journey leading up to it (for healthcare seekers) and the interlocking spaces and events around it. This encompassed both **Immersive life fabric** and **Contradictory Spaces**. The task was shaped by the space, as described above, through roles and institutions, as well as practical realities. The physical and temporal spaces of healthcare services, the high patient load and short staffing, and institutional failures such as drug stock-outs, all created a pressured environment for the encounter. Space directly shaped doing, through these features, among others.

The interactions between features of the space and the person with an impairment also produced varying experiences of disability within the healthcare seeking process. Practical considerations of physical access, transport and the social and sensory environment, among others, created constraints unique to the disabled healthcare seeker, for example the unconfined nature of the district hospital for a person with a mental illness, which rendered him a serious risk to others.

The encapsulated nature of the district hospital encounter was a critical shaper of both task perception and doing for the healthcare worker. With no personal responsibility for the healthcare seeker beyond this once-off interaction, healthcare workers' incentive to address patients' needs successfully was secondary to the motivation to cope with the setting by making the encounter as brief as possible. Not having a sustained relationship with individual healthcare seekers over time, healthcare workers held very little information about their patients, limiting their capacity to identify and respond effectively to more complex needs.

Finally, healthcare workers who were physically very far removed from the life context of their patients, often lacked insight into the realities of living with a disability and accessing healthcare. They tended to make assumptions about what was reasonable to expect, and became frustrated when people failed to act in line with these expectations. They also had difficulty adapting their treatment to the needs of the individual, rendering care both less appropriate and less accessible (for example because people were expected to make repeat visits to hospital in a short time-frame, which was unaffordable). By contrast, the clinic staff were often better able to fit their interventions to the setting, and had access to valuable additional information about the healthcare seeker, her social situation and her illness. Unfortunately, these workers held limited clinical power, and found that their reports and requests to hospital doctors were often ignored.

4.3.3. The relationship

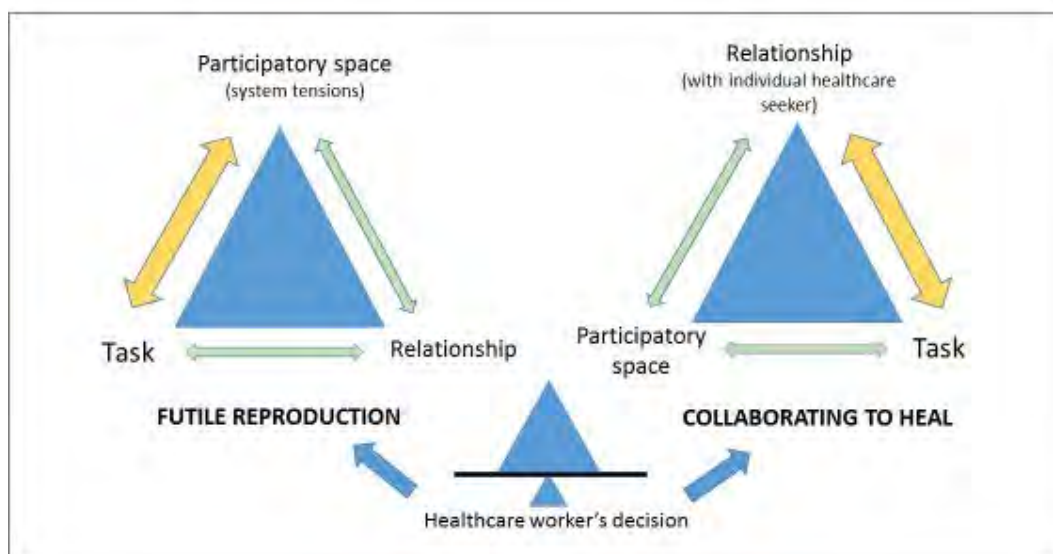
The relational dimension of the encounter was woven into all of our participants' accounts, and the quality of interaction seemed to be a powerful determinant of satisfaction with care. Not only did people appreciate the experience of respectful treatment, but they associated it with more skilful and effective treatment, or even considered these one and the same. Further, a positive relationship experience seemed to outweigh other negatives, including long waiting times, financial cost and even the lack of a solution for the presenting health need. This was particularly important for our participants, who experienced particular difficulties in the healthcare seeking process, multiplied over time and across a variety of problems. Where a health issue could not be readily resolved, or required ongoing treatment, a positive and trusting relationship with healthcare workers seemed to reduce distress, and support sustained engagement with the health system.

The theme **Collaborating to Heal** described the relational qualities valued by participants, as well as the ways in which this was enacted in the 'doing' of the encounter. By contrast, **Futile Reproduction** was characterised by a disconnection of healthcare worker from patient, and a manner of 'doing' that was shaped by formulae and pragmatic considerations, rather than personal engagement. It was clear that the same activity could be carried out in ways that either affirmed the relational connection, or excluded it, and the same could be true of information given. The socio-cultural setting in which participants lived, shed light on their close attunement to the relational dimension of healthcare, and the weight this had for them.

4.3.4. Two versions of the triangle: Futile Reproduction, Collaborating to Heal

The ways in which each element of the triangle shaped doing varied substantially, and actors had some degree of choice about which aspects were salient for them. The engagement dynamics of the two categories describing healthcare workers' 'doing', are captured in the diagram.

Figure 8: Two versions of the triangle



The left-hand triangle represents **Futile Reproduction**, where healthcare worker doing is most strongly shaped by the space of the healthcare institution. Coping with the demands of the working environment is the primary task, with very little weight given to the healthcare seeker before them, their specific needs, and the relationship dimension of the encounter.

The right-hand triangle represents **Collaborating to Heal**, where the relationship with the individual is placed uppermost, shaping the perceived task and motivating the healthcare worker to negotiate and overcome the constraints of the space in order to address the need.

The image of the engagement triangle balanced on a fulcrum in the centre, indicates the pivotal role of the healthcare worker's approach in determining the nature of the encounter. The relative powerlessness of healthcare seekers to shape what happened was clearly portrayed in the findings, and **Quiet Autonomy** represented their coping and adapting within the considerable limitations on their options. The healthcare worker's decision to engage relationally or not, was the balance on which the encounter turned, with far-reaching implications for the success of healthcare seeking.

4.4. The plot: Capability Suck, Capability Release

By exploring people's healthcare seeking through an occupational lens, it was possible to trace (to some extent) the capabilities available to them, as these were accessed, mobilised and leveraged to achieve other capabilities. Specific patterns of capability deprivation and possibility varied across situations, reflecting the complex interplay of factors comprising disability and poverty, with personal, socio-cultural and institutional strengths in the rural setting. People's agency in negotiating their opportunities and constraints, was foregrounded.

The stories revealed how participants experienced health needs as capability deprivations, often choosing to seek healthcare because an existing condition was preventing them from participating fully in their lives. While this often included symptoms such as pain or physical incapacity, participants frequently explained their distress to us in terms of what they were no longer able to do or be. It was marked how conversations with healthcare workers were nonetheless confined to symptoms, resulting in judgments about the "realness" and "seriousness" of complaints that took little account of healthcare seekers' own evaluations and priorities.

A range of capabilities was required to seek healthcare, including ability to travel safely, to cover access costs, and to negotiate the health service successfully. Trade-offs frequently had to be made, for example spending money on transport might mean using resources intended to buy stock for a small business. Pursuing the capabilities attached to the health need, might mean sacrificing the capability to maintain a successful enterprise, and to continue providing for one's household.

The precise resources and abilities needed to realise these capabilities could be understood through the multidimensional exploration of occupations making up this process. Rural residence and poverty emerged as significant conversion factors, making clear how the demands of healthcare access could be entirely different in this setting, from those of communities elsewhere. Disability emerged as an even more powerful conversion factor, interacting with the other two in ways that consistently disadvantaged and rendered vulnerable our participants and their households, relative to their neighbours. The specific impact of common barriers such as financial cost and waiting times, was shown to be quite different for this group compared to their peers, often in ways that were hidden from healthcare workers. For example, long waiting times at the clinic could mean that a person with a mobility impairment, who took a long time to walk home, would be at risk of violent crime due to travelling after dark. Similarly, rural residents were disadvantaged by the first-come-first-served

queueing system at the hospital. Not only was their transport many times more expensive than that of urban dwellers, but they were not able to arrive as early, which meant waiting long hours, and sometimes being told to come back the following day to be seen. This greatly increased not only the financial burden of seeking care, but also the time cost.

It was clear how the nature of engagement within the clinical encounter had powerful implications for participants' subsequent life trajectories. As Figure 6 shows, the two different kinds of encounter in the participatory spaces of the health service reflected back into the life fabric, producing multiple effects and consequences generally invisible to the healthcare workers.

For our participants, the balance between resources expended to access healthcare and the functioning regained by doing so, might be tenuous. **Futile Reproduction**, coupled with the limited choices and power of people with disabilities within the broader environment, could create a 'trap' in which participants expended increasing amounts of time, money, energy and opportunities to seek healthcare which did not justify these costs. This was termed **Capability Suck**, and was unfortunately common across our cases. Sibongile's story epitomised this narrative, with the activity intended to increase his capabilities (to work, to be free of pain) actually eroding these very things by the characteristics of the system and the environment. While his drive to be fit to work was for the sake of his family, the journey to fetch ferrules removed his protective presence from the house, exposing them to risk of attack.

The contrasting ideal outcome of healthcare was the **release of capabilities**, both by restoring function and well-being, and by freeing up resources previously used on healthcare seeking. This was unfortunately seldom seen for our participants, although Nozukile's story became one such example. Healthcare seeking was clearly an ongoing trade-off between capabilities sacrificed and capabilities gained. 'Capability equilibrium' could describe the character of sustainable and effective healthcare engagement for chronic disease or disability.

4.5. Summary of Chapter 4

This chapter has described the engagement of rural people with disabilities with healthcare workers in the PHC interface, first through a set of five stories of healthcare seeking, and then through an explication of emerging themes. The engagement in the participatory space unfolds across two separate worlds: the life context of rural people with disabilities, and the contradictory and conflicted space of the health system. People with disabilities negotiated both spaces with agency and effort, but the nature of the engagement was determined by how healthcare workers chose to approach the relational encounter, most often characterised by a sense of "letting the calf go to the cow": appearing to do one's job but failing to do so. Engagement in the clinical encounter was captured as a dynamic of task and relationship, shaped by and shaping the participatory space, and unfolding in the things that people actually did in the encounter (occupations). Collaborative and respectful relationships were shown to have far-reaching effects, producing positive outcomes even where a technical solution for the health need wasn't found. By contrast, healthcare workers' more typical approach of simply going through the motions, was shown to be at best ineffective, and at worst destructive of capabilities in the life fabric.

Chapter 5: Discussion

5.1. Introduction

In this chapter, I address the final objective of the research, considering how empowered engagement between rural people with disabilities and PHC workers might be strengthened. The study led us to think differently about both empowerment and the kinds of engagement through which it could be enacted. The clinical encounter was identified as the pivotal participatory space within the interface, with the relationship between healthcare seekers and workers its defining dimension. A close examination of dynamics at this level opened up new possibilities for strengthening empowering relationships for responsive healthcare, making the case for longitudinality, rural outreach, and the reconceptualization of health as capability, as well as the inclusion of rehabilitation workers as essential members of the PHC team.

Following these arguments, the theoretical and methodological implications of the study are considered.

5.2. Strengthening empowered engagement: proposals for health systems

5.2.1. Reframing empowered engagement

The study confirmed that formal mechanisms for community engagement in PHC were not functioning, for similar reasons to those cited in the literature (e.g. a lack of resources, lack of clear roles and powers (Padarath & Friedman 2008)). It also demonstrated that the social, political and systemic conditions were not in place for either 'invited spaces' or typical social accountability activities to be effective, even had local capacity allowed (Mansuri & Vijayendra 2013; Flores 2011). Specific to people with disabilities were the problems inherent in representational participatory structures (Gaventa & Barrett 2010), and the social exclusion they experienced in everyday community life (Whiteford & Pereira 2012). These findings supported the case for exploring alternative ways for rural people with disabilities to engage healthcare workers to leverage their right to equitable and responsive healthcare.

The findings also extended our understandings of why people did not adopt the kinds of behaviour commonly understood as 'empowered', even when the opportunity arose. Western individualist notions of empowered behaviour were revealed to be culturally unacceptable and even socially risky, shedding further light on why these were not adopted by our participants. Golooba-Mutebi (in Falisse 2013) argues from a Ugandan perspective that in African societies, people do not hold leaders to account through direct confrontation, and therefore social accountability and other community engagement activities may be found unacceptable, by both community members and African healthcare workers. The same author argues elsewhere that it should not be assumed that poor people will be eager and able to engage local government in pursuit of their rights when the opportunity arises, for a range of social, historical and practical reasons (Golooba-Mutebi 2005). This was also supported by our findings: detailed insight into the life context of villagers revealed how the types of engagement championed by the health system and in the literature were frequently unrealistic or inappropriate in this context. People who were judged as 'disempowered' or 'not taking responsibility for their health' were frequently prevented from doing what was expected of them by circumstances. Expectations of healthcare workers presupposed the priority of certain health goals, which were often superseded in our participants' lives by other values or imperatives. Grut, Mji, Braathen et al (2012) argue similarly that such misinterpreted behaviour is produced by the context

of rural poverty, and call for a reconsideration of health system assumptions about how people should act. This is further confirmed in other micro-level studies of poor people with disabilities in South Africa (Braathen et al. 2013; Neille & Penn 2015).

All of these insights support the argument for contextual dynamics and specificities as the primary determinants of local action (O'Meally 2013), and for the need to rethink what empowered engagement could look like in such a context.

We began with the assumption that people exercised agency as a matter of course (i.e. made choices to pursue goals they valued and had reason to value), and that their choices made sense in the context of their lifeworld. This approach shed light on the kinds of goals they chose to pursue, leading to a rethinking of how health (in the context of healthcare seeking) for this group might be conceptualised. Participants showed a great deal of initiative, motivation, ingenuity and effort in seeking healthcare, dispelling any notions of passivity or lack of investment. The theme **Quiet Autonomy** articulated the subtle, often hidden practices of agency enacted even in the directive context of the healthcare facility, allowing us to trace the possibilities and constraints of the available participatory spaces. Schneider, le Marci, Grard et al (2010) describe a similar dynamic of engagement in their analysis of patients' tactics for negotiating healthcare at a South African hospital. They caution against overemphasising the agency of healthcare seekers within the system, arguing that this can obscure the extent to which the hierarchical and stressed service context constrains people's freedom to act. Our study supported this concern, and added to the evidence on how existing participatory spaces emerge and are used in a rural PHC context.

The clinical encounter emerged as the primary site for engagement between people with disabilities and healthcare workers. Although not conventionally considered part of community engagement, it offered possibilities not only for direct healthcare for individuals, but also for the emergence of micro-level responsiveness to local needs, and specifically those of people with disabilities. Our data showed that some healthcare workers were able to adapt services to the needs and constraints of our participants, where they had sufficient contact with these realities to do so. This depended on the healthcare worker considering the person in context and providing space for needs and concerns to be voiced, i.e. adopting a person-centred approach. The possibility of a bridge between community engagement and person-centred care has earlier been expressed by Marincowitz and Fehrson who described the latter as "the clinical method of participatory democracy" (1998, in World Health Organisation 2008a, p46). While the adaptations possible within the constraints of the system might be small, they could make a substantial difference to our participants, and sometimes resulted in changes that benefited many other community members as well. This micro-level responsiveness was more likely at clinic level, but also indicated ways in which the responsive potential of other participatory spaces could be strengthened.

The contextual realities that precluded conventional forms of community engagement lay far outside the control of both people with disabilities and healthcare workers. However, at the level of personal interactions between these groups, the potential emerged for a different kind of empowered engagement: one strongly rooted in human relationships, within which healthcare responsiveness was possible even in the presence of major health system limitations.

5.2.2. Relational empowerment

The relational dimension of the healthcare encounter emerged strongly as its defining feature in the experiences of people with disabilities. Positive relationships appeared to have the power to mitigate barriers to healthcare seeking, outweigh the challenges of long waiting times and financial costs, and produce positive outcomes, even without a medical solution to the presenting health need. This

confirms observations in the literature on access to healthcare (Goudge et al. 2009; Harris et al. 2014; Thiede 2005), as well as in the literature on therapeutic relationships in rehabilitation and family medicine (Polatajko et al. 2015; Worley & Ranzcog 2002).

The engagement triangle provided a means to explore how relationships emerged dynamically in the healthcare encounter. The links between physical and organisational aspects of the system, and the social interactions and attitudes of staff and patients, have begun to be documented in the trust literature (Gilson et al., 2005; Topp & Chipukuma, 2015), but have not previously been described at the micro level. This study adds the recognition of occupation unfolding in the space, mediating contextual, personal and relational factors, as the essential process of engagement. The dynamic interactions within the engagement triangle call into question the separation of technical and human aspects of healthcare in health systems thinking (e.g. Valentine et al. 2003; World Health Organisation 2007). Our evidence suggested that participants experienced healthcare interventions (such as examinations, prescriptions, and medical procedures) and healthcare workers' attitudes and manner of engagement, as an interwoven and interdependent whole, with the interpersonal relationship at its core.

The findings unpacked the elements of relationship that were valued (**Collaborating to heal**) in a way that bore striking resemblance to principles of person centred care. These elements included a reciprocal relationship, characterised by respect and shared responsibility for identifying and addressing the health need, with the healthcare worker willing to listen to the patient and consider her as a whole person, rather than in terms of disease or impairment alone (Kitson et al. 2013). Where our participants' views differed subtly from the literature, was in a greater emphasis on the sense of togetherness, mutual acknowledgment and reciprocal process, over the explicit content of the interaction (for example steps to educate the patient, and negotiate treatment approaches). Even without these specific elements, participants seemed to experience these relationships as empowering, fostering a sense of being able to cope better with their situation, even where material change to the health need might not be possible. Samman and Santos (2009), writing within the capabilities approach, propose that (dis)empowerment may be relationally created through the balance of power between individuals in a given situation. This seemed to be borne out by our observations, in that relationships with healthcare workers seemed to open up or constrain opportunities for participants to engage actively within the consultation. However, the power of positive relational dynamics to transform the clinical encounter went beyond the purely instrumental, and extended outside the encounter itself. Ramugondo and Kronenberg (2015) argue that human relationships are in themselves a primary motivator for occupational engagement, and this better explained their significance in the stories we heard. Our participants, embedded in an African culture finely attuned to the relational dimensions of everyday encounters, could be expected to be especially sensitive to this aspect of healthcare. The healthcare process as a whole could therefore confer either a sense of disrupted relations (and therefore greater distress and illness), or a healing sense of social belonging and coherence.

While this idea has obvious relevance in an African cultural context, there is reason to believe it may have wider human significance. Gunderson and Cochrane (2012) make a similar argument from the Leading Causes of Life (LCL) framework, describing how the 'causes of life' may be incorporated into an encounter with the health system, or contradicted by it, including sense of coherence, connection to others and experiences of agency. They describe the success of 'congregational health networks' in the US, in mediating the emergency healthcare experiences of people living with sickle cell disease. By mobilising existing social networks to support healthcare seeking, a medical and personal crisis may become an affirming experience of social connection, life coherence and agency. While this has

positive implications for healthcare efficiency and effectiveness, they argue that its primary value lies in promoting positive health, rather than ‘beating back death’.

These insights indicate that strengthening the relational dimension of the participatory spaces would facilitate empowered engagement in the PHC interface, of a kind that is both culturally appropriate and of wider human value. We identified two significant features of the space which created relational disjunctures between healthcare seekers and healthcare workers. The first was the encapsulated nature of the healthcare encounter in both space and time. The second was the differing conceptualisation of task, based on contrasting understandings of health held by the two groups. The following sections explore how these may be addressed within the current South African PHC system.

5.2.3. From encapsulated encounters to responsive relationships

The removal of the clinical encounter from the life context of our participants proved a significant limitation to effective engagement, particularly with doctors, who were key clinical decision-makers. Healthcare workers unfamiliar with the rural setting, and particularly with disability, frequently had unrealistic expectations of what was possible, causing frustration on both sides when these could not be met. Grut, Mji, Braathen et al (2012) found the same dynamic in their study of rural people with disabilities in a similar South African community. They argue that unless healthcare workers are able to understand people with disabilities holistically, as members of households and communities living in poverty, they will misunderstand their health choices and be unable to offer appropriate services. Neille and Penn (2015) similarly describe the complex array of contextual factors shaping access to healthcare for people with disabilities in a semi-rural South African community, specifically highlighting their experiences of physical vulnerability and violence. Altering certain features of the participatory space to support the building of sustained personal relationships, while bringing healthcare workers into contact with the lifeworlds of communities, could strengthen the empowering potential of the clinical encounter.

The PHC literature makes the case for longitudinality in the PHC system, i.e. arranging healthcare so that the same healthcare workers care for the health of a given set of households over time (World Health Organisation 2008a). Evidence indicates that this increases satisfaction with healthcare for both staff and patients, and improves efficiency and effectiveness via a number of pathways (Ferrer et al. 2014; Lee et al. 2013). While ongoing contact with a specific healthcare worker was often the case at clinic level by default, the same arrangement needs to be extended to doctors and other key professionals in PHC.

Current evidence on trust in health systems demonstrates the significance of social, political and historical dynamics in shaping the relationship between citizens and state, with the South African macro context posing particular challenges (Gilson et al. 2005; Flores et al. 2009). However, most of this work has only considered these relationships at societal and community level. This study goes further, indicating that relationships built up over time could facilitate the development of trust on a personal basis, even where trust between communities and the health system itself is low. In the context of a failing health system, as in the study site, this would position individual healthcare workers to offset service challenges through personal trustworthiness and relationships built with individuals over time. Naturally, this does not negate the urgent need for change at a macro level to

resolve these challenges at their roots, including the conflicted relationship between citizens and state.¹¹⁰

Longitudinality could play a particularly significant role for people with disabilities, alongside others with chronic health needs. A consistent and trusted point of entry into the system may facilitate sustained engagement with healthcare, resulting in better adherence to long term treatment, and management of complex needs through early identification and care coordination (Ferrer et al. 2014). Importantly, engaging such healthcare seekers over time would also allow healthcare workers to learn from their patients' experiences, and develop more effective approaches to disability-specific issues, as alternatives to **Futile Reproduction**. The healthcare workers in our study showed a significant lack of knowledge and experience of disability, rendering this kind of exposure particularly important, alongside formal disability training and the inclusion of rehabilitation workers in the PHC team.

The PHC literature recommends not only a sustained relationship with a specific healthcare worker, but also that PHC teams are allocated responsibility for the health of a specific population, whether people seek healthcare or not. This shifts the care orientation to encompass social determinants of health, prevention and health promotion, and builds in continuity of care (World Health Organisation 2008a). Our study showed how this might also operate at the level of the clinical encounter. Ongoing responsibility for a given patient would shift healthcare workers' perception of task from short-term coping to long-term resolution, motivating them to address health needs effectively on first presentation. This could help to interrupt the cycle of **Futile Reproduction**, and lead to more efficient and effective use of resources (both those of the health system and those of healthcare seekers).

The spatial encapsulation of the clinical encounter could be addressed by bringing it closer to where people live, as recommended in PHC (World Health Organisation 1978). While outreach¹¹¹ is more often promoted for the purpose of improving access to care for rural and hard-to-reach populations, our findings indicated that it could also play a critical role in enhancing appropriateness of healthcare. It was clear how healthcare workers at hospital level made assumptions about our participants based on lack of contextual knowledge. Conducting outreach to rural clinics would afford urban-based workers some exposure to rural community life¹¹², informing more appropriate assessment and intervention. Such knowledge could be carried over to their work at other levels of care, so that outreach could improve services not only for those who benefit directly, but also for the broader community.

Outreach by hospital- or district-based health professionals would also create opportunities to strengthen their personal relationships with clinic- and community-based staff. South Africa, like many countries facing severe human resources constraints, has adopted a task-shifting approach which allocates the bulk of primary care tasks to nurses at clinic level. While this has been shown to be an effective use of available resources, particularly in the context of the HIV epidemic, the lack of

¹¹⁰ Flores and colleagues argue, from the Guatemalan experience, that building trust at the community interface may also contribute to restoring this larger set of relationships (Flores et al. 2009). Evidently action is needed both from the top down, and from the bottom up, to address the problem.

¹¹¹ It may be ideal for health professionals to be based in communities on a full-time basis; unfortunately in South Africa, as in other LMIC's, the lack of human resources makes this unrealistic.

¹¹² Outreach of this kind could be argued to be more important for rural communities than for urban ones, as most health professionals are familiar with urban settings, while relatively few have been exposed to life in rural areas. Rural healthcare seekers, especially those with disabilities, face greater barriers to accessing healthcare, and the cost burden to rural households could be greatly reduced, not only by offering services nearer their homes, but also by equipping healthcare workers to take account of rural challenges when planning treatment.

supervision for primary health care workers in rural areas is a serious problem (Versteeg et al. 2013; LeRoux & Couper 2015). Task-shifting requires regular and skilled clinical supervision and mentoring to be effective, as well as a strong referral system (World Health Organization 2008). Our findings revealed weak links between professionals at hospital level and PHC staff, resulting in patients often being shunted back and forth between the two, without coordinated action or consultation. Not only did clinic nurses not have access to the technical guidance of doctors and others, but we noted how the rich contextual knowledge of PHC staff was blocked or lost at the next level of care. Face-to-face relationships between clinic and visiting healthcare workers could facilitate more efficient use of both groups' expertise, by allowing each to inform the other in patient care. Again, personal relationships could potentially overcome some of the limitations of existing referral systems. Le Roux and Couper (2015) make the argument for outreach to clinics by professional teams based at rural district hospitals, from the perspective of clinical support and oversight for clinic staff. Our findings suggest that the transfer of knowledge in the opposite direction is as much needed.

By restructuring the PHC system to include longitudinality and rural outreach for key members of the healthcare team, the potential for empowering and empowered relationships in the interface could be strengthened. The de-encapsulation of the clinical encounter, leading to closer contact between healthcare worker and community over time, creates the conditions for micro-level responsiveness through person-centred care, even in the absence of other forms of community engagement. However, for this potential to be realised, it is critical that healthcare workers and people with disabilities approach the encounter with a shared idea of its purpose. We turn now to consider how health could be reconceptualised to make this possible.

5.2.4. Reconceptualising health

The study raised the question of how healthcare workers and participants perceived the task of a clinical encounter, allowing for the possibility that this may differ between actors. Much health systems literature seems to take for granted a single, unambiguous purpose for a given healthcare visit, based on the assumption that 'health' means the same thing for all concerned. A different approach has been adopted by medical anthropologists (Helman 1994), rehabilitation workers (World Health Organization 2010a) and family medicine practitioners (Greenhalgh 2006), who acknowledge multiple conceptualisations of health, and the need for negotiating these meanings within the clinical encounter.

Among our participants, with their often chronic health conditions and impairments, health seemed to be conceptualised in terms of participation in valued life roles and endeavours, rather than in terms of body structures and functions. The **reductive gaze** which interpreted health needs in biomedical (and often disease) terms, failed to capture the personal and contextual factors at play, and tended to minimise participants' experiences of ill health. By contrast, understanding health in capability terms allowed for the possibility of health in the presence of impairment or chronic illness, and opened up the potential for a more productive and hopeful engagement. This is a significant finding in the light of South Africa's growing burden of chronic disease and disability, and resonates with the debates in the literature around defining health for today's population, both locally and internationally (Huber et al. 2011; Horton 2009; Law & Widdows 2008).

A capabilities understanding of health was also able to encompass the healthcare seeking process itself as either producing or reducing health, through the plot of capability suck or release. This interpretation helped to make sense of people's decisions to pursue or abandon engagement with health services, recognising that the pursuit and engagement itself was seldom capability (or health) 'neutral'. The trade-offs we observed in these decisions, between (potentially) biomedically defined

health outcomes and other valued aspects of being, echoed Sen's argument for the importance of choice in defining health capabilities (Sen 1999; Ariana & Naveed 2009). Bostan, Oberhauser, Stucki et al (2014) provide empirical support for this proposition, in a study correlating self-reported general health with 'lived health' rather than biological health, for a large sample of people with disabilities in Spain ('lived health' was defined as a person's level of functioning in context).

There is ongoing debate in the literature regarding the fit between the capabilities approach and the ICF (Bickenbach 2014; Mitra 2014). In our study, the shortcomings of the ICF in excluding resources and personal choice pertained (Mitra 2014). The flexibility of the capabilities approach was significant in allowing cultural conceptions of health to be incorporated in people's health goals (Law & Widdows 2008). As a broad lens for human development, the capability approach could encompass structural factors unrelated to health condition that shaped people's life opportunities (for example aspects of poverty and rurality), capturing the intersectionality of gender, race, socio-economic class and rurality (Ropers-Huilman & Winter 2010; Emmett 2006). It could also be applied to people who did not have a health condition, so capturing the developmental impact of disability on household and family members. While the ICF offered a useful model for the interlocking aspects of impairment and functioning in context, the capabilities lens offered a complementary perspective, situating disability in the broader context of rural development.

In all, the capabilities lens proved a more inclusive, context-sensitive and pragmatic approach to the purpose of a healthcare encounter, and most significantly, also aligned with how participants themselves saw their needs (Bostan et al. 2014). This offers considerable promise as a basis for more people-centred health systems, offering a framework for health that goes beyond disease, to understand the whole person in context.

5.2.5. Disability and rehabilitation: essential dimensions of PHC

While this paradigmatic shift among generalist healthcare workers is important, the PHC staff in our study site still lacked the expertise to facilitate our participants' translation of basic health capabilities, into the participation they valued. This is the role of the rehabilitation team, including occupational therapists, physiotherapists, speech and language therapists and audiologists¹¹³, and most importantly, community-based rehabilitation workers. Besides working directly with people with disabilities and their families, rehabilitation staff also constitute a resource for the broader PHC team, providing both formal and informal training on disability, and specific input on adapting health services to take account of disability. Where disability is broadly conceptualised as arising from any health condition, and not only permanent impairment, the experience is likely to affect a large number of healthcare seekers, particularly in rural environments, and therefore should be considered as a critical issue for healthcare access and ultimately, universal health coverage¹¹⁴.

5.2.6. Summary

The prevailing sense of healthcare workers' engagement with people with disabilities was that of "letting the calf go to the cow": appearing to do one's job, but not actually doing it. However, this discussion has presented the significant opportunities for more empowered and empowering engagement between communities and PHC workers, which exist within the clinical encounter itself. Even in the context of considerable health system failure, personal relationships characterised by collaborative process and a shared understanding of health as capability, may strengthen access to healthcare over time, and allow for micro-level responsiveness to local needs. Suggestions have been

¹¹³ These are the cadres currently employed by the Department of Health, at least in theory. The employment of generic as opposed to profession-specific mid-level workers is an ongoing contention.

¹¹⁴ See Sherry 2015 for a more detailed discussion of rehabilitation in PHCR in South Africa

made for relatively simple adaptations to the current PHC system, which could support such interactions. The construct of disability emerges as a critical consideration in the 'fit' between people with health needs, their environment and the health system, calling for urgent attention to more inclusive system design, and for rehabilitation as an essential component of PHC.

5.3. Theoretical implications: Capturing complexity

The study aimed to contribute to theory informing the development of more equitable and responsive health systems. While its scale was extremely small, this allowed for a depth of investigation that revealed considerable new information, against which existing concepts could be tested. As outlined in Chapter 2, the literature points toward a significant role for micro-level dynamics in determining actual engagement between communities and PHC workers, and this research was able to address the gap in knowledge about such dynamics for rural people with disabilities. Further, it demonstrated the value of both occupation and narrative as lenses through which these things may be studied.

The considerable variation in the stories and experiences of our eleven participant households confirmed Balabanova et al's (2006) argument for the complexity of health systems interactions, including their extreme sensitivity to contextual shifts and wide variability across time and community setting. Through our participants' unique stories, we were able to observe how healthcare engagement was embedded in their daily lives, as they met life challenges and applied their energies to valued goals. At the micro level at which health-related choices were made, it was clear that an almost boundless variety of factors came into play, including but not limited to those related to the health system itself. This angle gave substance to the claim that health systems form part of the 'social fabric'. It also underlined the impossibility of a universally applicable model for understanding the engagement between communities and health services.

Balabanova and colleagues (2006), while making this same argument, identified the potential of certain 'sites of complexity' as foci for the study of local dynamics. These authors identified three such sites, i.e. the temporal dimension of healthcare engagement, the socially embedded nature of health decision-making, and the dynamic interactions where community members engage with healthcare workers. All three were explored and found to be significant in our study, as empirical application of the concepts surfaced elements of healthcare engagement not well captured in the literature.

Longitudinal stories of healthcare seeking revealed key aspects of engagement which could not be surfaced without this temporal dimension. For people with long-term illness or impairment, their history of healthcare seeking was critical in understanding current choices, and also shed light on the sustainability of chronic healthcare, an issue also raised by Goudge and colleagues in another rural South African community (Goudge et al. 2009). Further, this perspective demonstrated how complex needs required engagement with different levels and types of service within the health system at different points, and how referral networks, relationships and coordination within the system could obstruct or enable access to the needed healthcare. While empirical evidence on healthcare engagement for people with disabilities confirms this as a significant issue (Hwang et al. 2009), existing models of access tend to ignore access within the system itself (Balabanova et al. 2006). While the fragmentation of the South African health system has been acknowledged in the literature (Mayosi et al. 2012; Naledi et al. 2011), this has not been adequately explored in studies of access to PHC, particularly for people with disabilities.

The socially embedded nature of health decision-making emerged vividly in our stories. The relational orientation of Xhosa/Bhaca culture dictated clear social roles and responsibilities, with emphasis on

doing things together, and continually affirming kinship ties and social solidarity. The interdependence of household members was increased by socio-economic constraints, so that one individual's healthcare seeking had significant implications for others' opportunities. The use of time and energy was similarly pressurised (Arora 2015), so that time taken accessing healthcare was a significant burden.

The dynamic interaction of rural people with disabilities and PHC workers in the interface was the focus of this study, and has already been discussed in detail. 'Degree of fit' between community and health system was identified in the literature as a promising construct in understanding engagement (Penchansky & Thomas 1981; Thiede et al. 2007), but the findings took this a step further, portraying this relationship as a site for active mutual adaptation. This has implications for the theorisation of healthcare access, calling for the attribution of more active roles to both communities and healthcare workers, as well as the argument for seeing healthcare as a collaborative process rather than a pre-determined product to be 'delivered'. It also supports the central tenet of PCHS, namely that health systems are relational systems (Sheikh et al. 2014).

The three 'sites of complexity' described here are not claimed as exhaustive by their proponents (Balabanova et al. 2006). This study contributed a further lens or focus for the complexity of local health system dynamics, namely the construct of occupation.

Occupation, conceptualised as transactional, context-embedded and multi-dimensional, offered a practical lens to capture human engagement in the PHC interface, drawing together physical, social, personal, cultural and practical factors, and demonstrating how these interacted over time. In contrast to much health research that describes a range of barriers and facilitators influencing access (e.g. Van Rooy et al. 2012; Swartz et al. 2011), this study went a step further by exploring what people actually did in given situations. The research began with the observation that people's responses to the same set of challenges varied widely (Long 2003), and the occupational lens allowed us to examine, at personal and household level, how and why this was, for our participants.

Conceptualising healthcare seeking as occupation also allowed for detailed study of disability, poverty and rurality as conversion factors in access to healthcare (Sen 1999). Our stories supported the literature's focus on financial, transport, temporal and attitudinal barriers to healthcare access (Swartz et al. 2011) but offered a richer and more nuanced understanding of how these interacted for individuals, and the ways in which people could be differentially affected by them. This has important implications for equity in health system design. The detailed and practical level of knowledge gained through this micro level of analysis, offers a strong basis for designing locally appropriate measures to overcome such barriers.

Because this study is primarily situated within HPSR, the full potential of existing scholarship on occupation has not been explored in detail. This research has however offered preliminary indications of the value of combining these two areas, for both HPSR and occupational science itself.

5.4. [Methodological reflections](#)

The study employed a variety of methods to address the challenges of cross-cultural research, including narrative interviewing, immersion in context and working with a local co-researcher. As the work progressed, these approaches were adapted and developed further.

Asking people to tell their stories yielded readier responses and richer data than specific questions from the researchers, confirming narrative inquiry as a culturally appropriate approach (Neille & Penn

2014; Czarniawska 2004). I was cautious however in applying conventional forms of narrative analysis, given the culturally embedded nature of story-telling. Not only was it difficult for me to access the language used directly, but I did not share the repertoire of tropes and references within which their stories were framed (Greenhalgh 2006). The process of co-analysis with Xaks confirmed this strongly, and also surfaced the ways in which the story-telling context and audience (i.e. the research interview) shaped what was said and not said (Holley & Colyar 2010). In this way, the stories shed light on the relationships between ourselves, our participants and healthcare workers, adding to the layers of data we had hoped to generate about the participatory spaces of the interface.

From the stories of individuals, we moved towards including multiple voices, including our own, in building each case study. By juxtaposing the various tellings of the same series of events, the tensions between actors' perspectives, interests, and understandings emerged. It was important to remain reflective and reflexive about our own role in both the story itself and in constructing the version to be told in the research. The process of writing the stories in Part 1 of Chapter 4 was a reflective and interpretive exercise in itself, as was the sharing of these stories with others in the course of analysis and writing up.

The act of immersing myself in the rural community context formed a crucial background to my interpretation of the other data. While the period I spent living in Kwabisi was quite short (three months), it was sufficient to shift my perspective and challenge previous assumptions. The logistical challenges and time demands of routine tasks placed the occupations of healthcare seeking in context for me, with the physical experiences of these things adding greatly to my understanding. The following excerpt from my journal illustrates this:

"I watched myself picking my way across the muddy yard yesterday in my shweshwe¹¹⁵ skirt with my pail of water, and I laughed. I find myself watching [my neighbour], and then working out why she does what she does. Much of it is so practical. When I find myself bending in half and leaning an elbow on one knee to wash my dishes in the pail the way she does, I realise it makes perfect sense. Some ways of doing things are passed on as "custom", but there are good reasons for them. The shweshwe skirt is my favourite discovery. Perfect for a wide range of weather conditions – cool in the heat, or you can wear tights underneath when it's cold. Dignified throughout the wide range of physical activities and positions required by housework without ergonomic countertops and indoor taps. Most importantly, if there's no toilet and you need to pee, you can squat without revealing anything – something you can't do as a woman in trousers! ... Shweshwe, and wearing a skirt in itself, are also powerful cultural symbols: you are recognised as a woman when you wear a skirt...

Back to occupations, I begin to see myself as somewhat disadvantaged out here. My arms are weak and tire quickly when washing filthy socks by hand or squeezing out wet towels. I would be in serious trouble if I had to provide a household with water, the most basic thing – I just can't do 20 litres on my head, and it would take me all day to get enough. My potato peeler and tin-opener I now see as assistive devices, compensating for my lack of skill in doing either task with a knife." (Field notes, round 1)

This kind of experience was particularly valuable for the study of occupations, accessing tacit elements of everyday activities I would not otherwise have encountered (Huot & Rudman 2015).

¹¹⁵ Cotton print traditionally worn by Xhosa women. Married women wear long skirts (never trousers), and headscarves.

Spending time doing things with other members of the community, even when not directly related to the research question, was important in giving me a sense of how things unfolded and how people interacted in this socio-cultural context. Despite several years of working in a similar area, including many home visits, this immersion experience was crucial in teaching me to 'hear' our participants, and particularly what was 'said' in the many pauses, silences and roundabout approaches to a conversation. Complemented by Xaks' explication of the many evasions and allusions in our interviews, this made me aware of how subtle and understated, often to the extent of being cryptic, was people's style of communication. This brought my Western, text-focused and literal research approach into serious question, and made me understand why my plainest statements often seemed to be met with suspicion or apparent misunderstanding. It also rendered it impossible to use conventional qualitative analysis approaches on the raw transcripts, and led to the development of our co-analysis/interpretation method, described in Chapter 3. While often laborious, this process was incredibly rich, and confirmed my decision not to rely on literal translation/transcription and my own interpretive capacity.

Xaks, as first my research assistant and later my co-researcher, was essential to the feasibility and success of the study. Our relationship was not without tensions, as I struggled to balance my research plan and responsibility for leading the process, against my dependence on his guidance and local knowledge. Cultural differences in communication were an ongoing challenge, but also a source of learning, and his capacity to reflect on issues that arose led to better understanding between us. Our relationship became another space in which dynamics between actors in the study were reflected, most conspicuously when it came to discussion of local beliefs.

In his interactions with our participants, the contrast between their responses to him alone, and to me, were often telling. Through both his identity as a local Bhaca man, and his personal skill and rapport with people, he was able to access knowledge from which I was excluded, which also helped to distinguish my own impact on the data generation from other issues.

Xaks was perhaps the most valuable in managing our relationships with participants. As I learnt more about local ways of being, and the weight placed on relational harmony and reciprocity, it became clear that Western research ethics were completely inadequate to guide my acceptable conduct here. He was able to interpret the research process in ways our participants could understand, and also to identify and dispel misconceptions about what we were doing. He also played the crucial role of maintaining relationships in my absence, including after the data generation ended, and communicating ongoing news and occasional needs to me, as well as advising where our involvement might be appropriate.

Together, all of these measures took me further in understanding what was happening in the study site, and helped me act more ethically and appropriately. The intensive nature of this learning process was striking, as was the depth of insight I gained through it, in spite of prior years spent working in a similar context. This underlined the challenge faced by healthcare workers in understanding and responding to the lived realities of rural people with disabilities, even those who come from a shared cultural background. The practical value of the knowledge we gained was reinforced for me, as I found myself incorporating it into my clinical, teaching and advocacy activities even before the study was complete.

5.5. Summary

This research project addressed the gap in the literature concerning the micro-level dynamics in the interface between rural people with disabilities, and PHC workers. While finding agreement with the existing literature on healthcare engagement for rural people with disabilities, it also extended this knowledge through a fine-grained analysis of relational dynamics in the clinical encounter, linking these to personal, contextual and health system factors. While the essence of healthcare workers' current engagement with people with disabilities was most often characterised as formulaic, superficial and largely ineffective, the rare instances of genuine relational engagement showed startling power to promote healing.

Disability emerged as a critical consideration for PHC services, and specific recommendations to strengthen healthcare engagement for this group included longitudinality, rural outreach and rehabilitation workers as core members of the health team.

Conceptually, the findings support the argument for complexity and high context sensitivity in the health system-community interface, and offer the constructs of occupation and narrative as productive avenues for capturing this.

Methodologically, the study illustrated the challenges of cross-cultural research, and explored some useful approaches to these, including use of narrative, contextual immersion, and partnering with a local co-researcher.

Chapter 6: Conclusion

6.1. What if...

When Nozukile first began to feel ill, she explained her problem to the clinic nurse. The nurse listened carefully, wondering if her distress had anything to do with the death of her mother a few months previously. She remembered how Nozukile's mother had always come to the clinic with her daughter before, protective of this youngest child with her disability, even when she was an adult. The nurse tested Nozukile's blood for diabetes, listened to her heart, and booked her to see the doctor when she visited the clinic the following week. The doctor, when she saw Nozukile, asked how the family was coping since her mother's death, and whether Nozukile's younger sister's asthma was bothering her again. She followed up the nurse's examination with further checks, finding nothing to explain the symptoms, and reassuring Nozukile that her heart seemed to be working fine, which seemed to be her main worry. The doctor prescribed some medication for the pain, and asked Nozukile to see her again in a few weeks' time. Although Nozukile continued to have occasional episodes of illness, the healthcare workers noted that her distress decreased, and that over the months she seemed to become happier and more confident in her new role as head of the household.

A year or so after the district health team began making changes to its approach, the doctor noticed that she wasn't seeing as many patients of Nozukile's presentation at the hospital as before. She also found herself feeling both more compassionate and more confident in treating them, since getting to know her patients better and seeing them get well over time.

* * * *

Phindile's brother noticed first he was beginning to relapse while the two of them were herding the neighbour's cattle on the mountain together. He always took Phindile along with him, although their neighbour didn't pay anything extra, because the community rehabilitation worker (CRW), together with the occupational therapist (OT) from the district, had explained Phindile would do better if he had something to do every day. The brother noticed they were right, observing his skill with the animals, and how the daily routine seemed to keep him motivated. He had not smoked dagga for months, and the exercise helped him to sleep and eat well.

One day on the mountain though, he noticed Phindile was much quieter than usual. When he asked what was wrong, Phindile told him he was hearing voices again. At the mental health support group they attended at the clinic, they had been taught about the different symptoms of schizophrenia, and had learnt to identify the early signs of a relapse. The brother went that evening to speak to his neighbour the CRW, and the next day they went together to the clinic, where the nurse assessed him. After speaking to the doctor on the phone, she adjusted one of his medications to try and keep him from getting worse.

When the doctor visited the following week, she listened to the report from the nurse, the CRW and the family, and commended them for their quick action. It emerged that Phindile had begun skipping his medication, because the side-effects were becoming unpleasant. The doctor reassured Phindile and his family, and adjusted the prescription to counter the side-effects for the time being. She discussed the case with the district psychiatrist at their next meeting, and decided to admit Phindile to the district hospital psychiatric ward in order to change his drug regime in a controlled environment. On the ward, the occupational therapist assessed Phindile's participation in various daily activities, and discussed his level of functioning at home with the CRW. Once his condition was stabilised on the new medication, a meeting was held between the family and the healthcare team, and a revised treatment plan

discussed. The OT counselled the family about current challenges in Phindile's behaviour and functioning, and helped them identify strategies to include him more in household activities.

Back in the community, the family shared the story in the monthly support group. Other members began to identify their own struggles with side effects, and decided to discuss these with the nurse. Encouraged by the OT and the CRW, Phindile and his family began to extend his responsibilities in the household, and Phindile slowly began to feel more like a man in his community. A few months later, he even ventured to attend the weekly imbizo with the other men.

* * * *

When Sibongile first developed severe back and shoulder pain, he mentioned it to the community rehabilitation worker. The CRW lived near him, and had noticed how active he had been since getting his own carpentry tools, walking long distances to do jobs for people. She asked at the clinic about getting replacement ferrules, and booked him to see the physiotherapist when he visited at the end of the month. The clinic manager spoke to the pharmacy depot and arranged regular deliveries of new ferrules with their drug orders. The CRW's and nomakhayas identified a number of other people they knew who were also struggling with their worn-out crutches, and took them replacement ferrules when they visited their homes. Sibongile would collect several sets when he visited the clinic, as the CRW explained to the nurse how much he was walking. She also sometimes delivered them to him at home when he ran out. With the time and money he saved on going to get new ferrules, Sibongile was able to build his business, and also to work on his homestead, installing a water tank and digging a vegetable garden. The physiotherapist treated him for the existing back and shoulder pain, and referred him to the orthotist for new shoes. When the orthotist from Mthatha visited the district hospital on his monthly outreach, Sibongile was assessed. When the shoes were ready, the physiotherapist brought them to the clinic for him. The CRW mentioned to the physiotherapist how quickly the ferrules seemed to wear out, and he investigated alternative products that were more hard-wearing. He wrote to the province to motivate for these to be included in the walking aids tender, and the following year they became standard issue. Once the issue had been raised, it emerged that other therapists in rural areas were identifying the same problem, and the change in ferrule helped hundreds of other crutch users around the country.

* * * *

Once the doctor began her outreach visits to Kwabisi, she started asking her patients at the hospital where they lived, as part of her routine assessment. She was stunned at how far many of them travelled to see her, and particularly when she found out what they paid for transport. It made her think far more carefully about booking return appointments, and she raised the issue at a team meeting. The rehabilitation therapists suggested a system for coordinating appointments between the different service departments, and after several months, everyone noticed that patients were keeping their appointments better. The team began to look at revising the outpatient queueing system to take account of rural travel and particularly people with disabilities.

* * * *

These vignettes imagine what interactions with PHC might look like for rural people with disabilities, with the system adjustments suggested in the previous chapter. While the changes made are relatively minor, the impact on both the community and the health service are potentially substantial. In the earlier stages of the research, the structural problems of poverty, rural underdevelopment and health system failure seemed overwhelming, but with time I began to see the restorative potential present in human relationships at the micro-level of the interface. There is no question that the macro level

conditions constitute serious human rights and social justice concerns and require urgent action, but there is considerable hope to be found in acknowledging what small changes by individuals can achieve.

The study began with the assumption that rural people with disabilities consistently exercised agency, pursuing goals they valued across their life context, including their interactions with healthcare services. Our findings confirmed how health-related behaviour and choices were best understood within a holistic conceptualisation of health, which included a powerful relational dimension, personal values and pragmatic trade-offs between different aspects of functioning. Finally, the study bore out the assumption that health systems are fundamentally human and relational, part of the social fabric, and highly complex at their interface with communities.

6.2. Contributions to scholarship

This study addressed a gap in the literature regarding the existing interface between rural people with disabilities and PHC services in South Africa. It succeeded in providing an in-depth description and analysis of this hidden aspect of the health system, which knowledge has relevance for local policy makers, health planners, clinicians and other stakeholders working in this setting. The findings and emerging theorisation also have wider potential application to marginalised populations in other parts of the world.

Methodologically, the challenges of the study led us to test and develop novel approaches to cross-cultural qualitative research. I had a unique opportunity as a doctoral student to spend far more time in the setting than is often possible for health researchers, and also had the advantage of 'insider' experience of the local health system from my past clinical roles. Most significantly, I had access to Xaks' rare level of skill and insight in facilitating research in this setting, and bridging the worlds of urban, Western-educated researchers and the rural Bhaca community. The co-analysis approach we developed to work with the interview data built upon these various sources, and responded to the cultural biases of conventional qualitative analysis. The Western emphasis on text and direct translation contrasted sharply with the communicative styles of this African community, in which context, implication and relationship were far more significant than spoken words. This finding raises serious challenges for qualitative researchers working with indigenous communities around the world, and it is possible that our approaches could be of use elsewhere.

Conceptually, this study combined theoretical perspectives in some new ways. The introduction of an occupational perspective on disabled people's engagement with rural health systems paves the way for closer collaboration between public health and rehabilitation researchers and practitioners. The application of the capabilities approach also positions health systems questions within the broader field of development. Although the conceptual fit between these various constructs has been previously identified to varying degrees, their application together in this study was unique.

6.3. Limitations of the study

An obvious limitation of the study was its very small scale, and the data generated were not exhaustive, due to the limited time and resources available. At the same time, the richness of new insights gained even within these constraints, spoke to the level of complexity and uniqueness in the health system interface, and the need for further study in this area. The findings allowed existing constructs and assumptions to be tested, and their limitations in this set of cases opened the possibility (even probability) that the same would be true elsewhere. Larger scale research employing quantitative methods would be necessary to test the presence and impact of the mechanisms and relationships described, in the greater population. This qualitative study played the role of exploring and describing a new area, in order to lay the foundations for further quantitative work, which could

be translated into concrete policy recommendations. It also offered information for comparison with the assumptions made in interpreting existing quantitative data (for example, the use of healthcare utilisation as a proxy for access to healthcare, is shown to be seriously problematic for rural people with disabilities).

Further work could test the research findings against other settings, including rural as well as other deprived areas, and with people living with other kinds of impairments. The case studies involving mental illness surfaced particularly complex dynamics, both socio-cultural and systemic, calling for more research among this sub-group of people with disabilities.

Although the sample attempted maximum variety, it also underrepresented women and children. Given the distinct gender roles in this community, and particularly women's roles in caregiving and household labour, further investigation of the experiences of women with disabilities is needed. Children with disabilities face particular developmental challenges, and have a substantial impact on the household over time; these should also be explored in more detail. The sample also included only one elderly person, possibly because the impairments associated with old age are not considered 'disability' in this context. This would however be an important group to include in the category for health systems purposes.

Finally, the study introduced but did not fully explore the potential of occupational science in increasing understandings of health systems as human systems.

6.4. Personal conclusions

This was not only an intellectual journey, but also a deeply personal one. I began as a clinician and activist, frustrated and a little despairing at the challenges of rural PHC, and rehabilitation in particular, not to mention my own lack of understanding of the community context. The experience of doing the research sometimes deepened these same feelings, but also provided the space to work through the questions, on both an intellectual and personal level.

In reflections recorded at the beginning of the study, my action orientation was vividly apparent. During data generation, I sought constantly for solutions to people's struggles, and worked hard to do what I could towards these. It was extremely difficult for me to step back from doing, to inhabit the role of observer and reflector. When I did, however, the insights gained were immense, and for me, life-changing.

During the period of the research, I was simultaneously engaged in a variety of rural healthcare-related activities, including clinical consulting for an NGO, support to junior occupational therapists entering rural practice and occasional undergraduate teaching. As a volunteer with an organisation representing rural rehabilitation therapists, I also became involved in health policy processes at national level. The stories of our participants, and the experience of living in Kwabisi wove their way into all of these things. An adapted version of Phindile's story was used in the launch of a national campaign for rural mental health, and in a newspaper article about the issue. Nontombi's story made me rethink how I approached mothers of children with disabilities when in a clinical role, and I discussed these ideas with the young rural OT's. The *nomakhayas'* situation influenced a lecture to students on managing CBR programs. When the national tender for walking aids came up for review, I wrote a motivation for including rural-proof ferrules. Perhaps most significantly, I took all of this learning with me into rooms with policy makers and high-level managers. While there was little room for the stories to impact such spaces directly, they made me acutely aware of the chasm between the

worlds of officialdom and policy (and sometimes also academia) and this part of South African citizenry.

All of these experiences illustrated the power of personal narratives to change thinking. Without scale or numbers, the stories made me test theories and assumptions, both my own and others, and became part of the imaginative landscape against which I reason, work and live.

I have made peace with the fact that my presence in Kwabisi has changed little for the people who live there. For some households, we were able to give information, make referrals or write letters that gave them access to services and resources to which they were entitled. For others, we had little or nothing to offer in exchange for their time and stories. As the data analysis deepened my understanding of their world view, I realised even more the weight and value of these things. I had many moments, reading over transcripts, when I could have kicked myself for missing that.

If the research left anything behind, it was in Xaks. Not only did he continue to visit people when in the area, but his activities in this and the previous two research projects brought him to the attention of the local Department of Social Development. Galvanised into developing their program for people with disabilities, they engaged him to help them set up disability forums in several areas. Together with the people of Kwabisi, he also organised a large intersectoral disability awareness event. Perhaps in time, these things will begin to shift disability a little more into the considerations of communities and service providers.

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Glossary of isiXhosa/isiBhaca terms

Bhuthi:	Brother, term of address for any boy or man of similar age to oneself or younger (older men are addressed as <i>tata</i> or father)
Burial society:	Community saving scheme for funeral cover. Funerals are enormously significant events in this culture, being an honouring of the dead, who are joining the ancestors and will forthwith oversee the fortunes of the family.
Dagga:	marijuana
Dig:	dignity, social standing
Fonkonko:	Something poorly made and easily broken, cheap junk
Gogo:	grandmother (term of address for older women)
Gqugqa/guruguru:	small pick-up vehicle fitted with makeshift seats, invariably heavily laden and crowded, and the main form of public transport in rural locations
Imbizo:	Regular meeting of elders, headmen and subheadmen, as well as other community members, for the purpose of sharing news, making decisions, judging local disputes, and other community matters.
Lobola:	Bride price, paid by the groom to the family of the bride, via an elaborate process of negotiation. <i>Lobola</i> is traditionally paid in livestock (especially cattle), but today commonly includes cash and/or household goods as alternatives. Costs tend to be exorbitant compared to average household incomes, making marriage inaccessible to many men, and thus preventing them from establishing themselves socially in the community.
Makhoti:	Newly married woman, who according to tradition must spend one or more years living in her in-laws' home and working for the household. <i>Makhotis</i> must prove themselves to their new families through hard physical labour, and are subject to strict rules and taboos regarding their behaviour, particularly to the male relatives of their husbands.
Nomakhaya:	community health worker
Pap:	maize porridge, a local staple
Piece job:	Ad hoc work, usually for a neighbour, such as helping with home building and repairs, fencing or mending furniture.
Sangoma:	Traditional healer
Shebeen:	Unlicensed local liquor outlet
Shweshwe:	Cotton print traditionally worn by Xhosa women.
Spaza:	Informal shop run from one's home, usually selling small quantities of essentials such as bread, candles, tobacco and sweets
Ubuntu:	African moral philosophy of personhood through connection to others

- Ukuthwasa:** The process of becoming a *sangoma*
- Umgalelo:** Community savings scheme in which each member makes a monthly contribution, and receives a share of the savings at an agreed time.
- Waskom:** Wash-basin, usually plastic or tin
- Zulu:** Local term of address for any fellow local resident, implying kinship

Appendix A: Ethical clearance: University of Cape Town Human Research Ethics Committee (HREC)

UNIVERSITY OF CAPE TOWN



Faculty of Health Sciences
Human Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
e-mail: shuretta.thomas@uct.ac.za

10 January 2013

HREC REF: 569/2012

Ms K Sherry
c/o Prof S Reid
Public Health & Family Medicine

Dear Ms Sherry

PROJECT TITLE: "OCCUPATIONS OF CITIZENSHIP": THE MISSING LAYER IN EMPOWERED ENGAGEMENT BETWEEN HEALTHCARE WORKERS AND RURAL DISABLED PEOPLE

Thank you for responding to the issues raised by the Faculty of Health Sciences Human Research Ethics Committee in your letter received on 24th December 2012.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year till the 15th January 2014

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/research/humanethics/forms)

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC. REF in all your correspondence.

Yours sincerely

Signed by candidate

PROFESSOR M BLÖCKMAN
CHAIRPERSON, FHS HUMAN ETHICS
Federal Wide Assurance Number: FWA00001637.

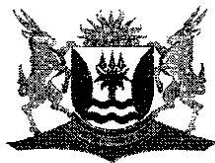
Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

s.thomas

Appendix B: Study approval, Eastern Cape Department of Health



Eastern Cape Department of Health

Enquiries: Zonwabele Merile

Tel No: 083 378 1202

Date: 07th March 2013

Fax No: 043 642 1409

e-mail address: zonwabele.merile@impilo.ecprov.gov.za

Dear Ms K Sherry

Re: "Occupation of citizens" The missing layer in empowered engagement between healthcare workers and rural disabled people

The Department of Health would like to inform you that your application for conducting a research on the abovementioned topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.
2. You will observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants. You will not impose or force individuals or possible research participants to participate in your study. Research participants have a right to withdraw anytime they want to.
3. The Department of Health expects you to provide a progress on your study every 3 months (from date you received this letter) in writing.
4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Epidemiological Research & Surveillance Management. You may be invited to the department to come and present your research findings with your implementable recommendations.
5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

Signed by candidate

DEPUTY DIRECTOR: EPIDEMIOLOGICAL RESEARCH & SURVEILLANCE MANAGEMENT



Ikamva eliqaqambileyo!

Appendix C: Covering letter for participants (English version)

To whom it may concern:

I am a researcher wanting to know more about how disabled people from rural areas work together with healthcare workers as they seek and use services. We know that as South African citizens, people who use services are supposed to be able to have a say in how these are run, but this doesn't always happen. I'm hoping to find out what small things disabled people and healthcare workers do when they meet that helps this kind of "active engagement" to happen more often. This research is being conducted for my PhD degree.

I would like to spend time with you as you either attend a service (e.g. a clinic), or render a service for disabled people (if you are a healthcare worker), and to talk with you about what happens. We will probably meet two to four times to do this, depending on what comes out of each event. I believe that if we can identify the strategies you are already using to be "active citizens" in health services, we can find ways to strengthen these, so that disabled people from rural areas can have more say in how services work.

I may ask if I can record our discussions, and the clinic visits etc that I attend with you. This is to help me remember what is said, so that I can give a right report. If you'd rather I didn't record, I won't do this. I will be working with an interpreter, so that we can always communicate properly.

You are under no obligation to participate. You can withdraw at any stage during the research, your wish will be respected and our work together terminated.

I undertake to ensure that your confidentiality will be protected: no-one reading reports of the research will be able to identify you. I will also do my best to ensure the research does not disrupt your routine, particularly as you access or deliver health services. If it ever happens that you or a member of your family is uncomfortable with any part of the research process, I would really appreciate it if you let me know.

You may contact me on 0766114063, to discuss any concerns you may have. I also need to inform you that, as a member of the health profession, I am obligated by law to report to the authorities any abuse of a child or disabled person that I might observe during the research. I would like to assure you, that if such an unfortunate thing should happen, I will inform you of my actions. Nothing will happen without you being notified.

There will be a report available at the end of the research, in both English and isiXhosa, for interested persons to read. I may also use newspapers, magazines or radio to share my findings with the public. My plan is also to share what I learn with the Department of Health, in the form of policy briefs. I will encourage you to read and comment on all accounts of what I have learnt and observed. Your name will not be used in any report.

I am not able to offer much in the way of compensation for your valued participation. Obviously, if I am aware of any resource from which you might benefit, I will inform you accordingly. If I make any request of you that costs you money (for example, taking transport to meet with me), I will reimburse you for this. I am not able to reimburse you for costs you would anyway have incurred in accessing health services.

Should you agree to participate in the research, there is a consent form to read and sign.

Thank you so much for your time.

Kate Sherry (Miss)

Researcher and PhD student, UCT

Appendix D: Consent form (English version)

In signing below, I _____ grant permission for Kate Sherry, a researcher and PhD student from the university of Cape Town, to spend time with me as I use/deliver health services, and to discuss with me what happens during these events, in order to learn more about small things people do to be “active citizens” with regard to health services. I understand the purpose and aims of the research that have been explained to me. It is also agreed that if at any point I wish to withdraw from the research, this will be respected, and my involvement with the research process will be terminated. I understand that withdrawing, or choosing not to participate, will in no way affect the care I can expect from state services, or any assistance with accessing services offered by the researchers.

The researcher has explained to me that my privacy and confidentiality will be respected, and that I will not be personally identified in any report of the findings.


I understand that I will not be paid for taking part in the research, except if it costs me money to take part that I would not otherwise have spent (e.g. transport costs to attend a meeting with the researcher). I understand that the researcher will not pay any of my costs to access health services, even if she accompanies me to the hospital/clinic.

Name: _____

Signature: _____

Thumbprint:

Date: _____



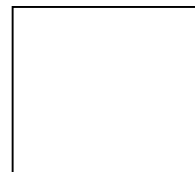
Witness (if participant is unable to read and write):

Name: _____

Signature: _____

Thumbprint:

Date: _____



Caregiver (if participant is unable to agree for herself)

Name: _____

Signature: _____

Thumbprint:

Date: _____

